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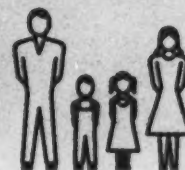
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ABSTRACT

This report provides basic information about parents with significant intellectual impairments and/or developmental disabilities and the programs and services in their communities designed to assist them. The report is based on reviews of 8 demonstration programs in New York State, record reviews, interviews with 41 enrolled families, and home visits to 25 enrolled families. The first chapter provides an introduction to the study, its methodology, and limitations. The second chapter looks at the parents and their families, including information on demographics; family structure; medical, mental health, and physical limitations; social histories; cognitive abilities; daily living skills; and parenting skills. The following chapter looks at the children and considers demographics, the clinical profile, their basic wellbeing, school performance, maladaptive behavior, and adaptive behaviors. The fourth chapter examines services received by the families, noting differing program models, funding differences, effects of family interests on services, intensity of service provision, nature of service provision, access to other community services, informal supports, and unmet service needs. The final chapter presents conclusions which note these parents' need for formal and informal supports, the importance of early intervention services and risk management procedures for their children, and the need for program staff skilled in working with this population. (Contains 15 references.) (DB)

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Parenting With Special Needs: Parents Who Are Mentally Retarded and Their Children

New York State Commission on Quality of Care
for the Mentally Disabled

September 1993

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Parenting With Special Needs: Parents Who Are Mentally Retarded and Their Children

Clarence J. Sundram
CHAIRMAN

Elizabeth W. Stack
William P. Benjamin
COMMISSIONERS

September 1993



NYS COMMISSION
ON QUALITY OF CARE
FOR THE MENTALLY DISABLED

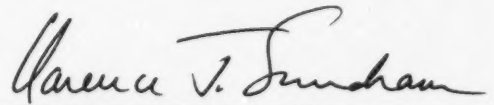
Acknowledgments

The Commission wants to express its deep gratitude to the families served by the eight parenting programs reviewed. Through their stories and experiences, recast and retold to protect their confidentiality in the vignettes in this report, the Commission was able to obtain a first-hand perspective of parenting with special needs that it would never have been able to construct from an empirical data base alone. The Commission is especially appreciative of the 25 families who invited Commission staff into their homes to meet their children and to learn more directly about their daily lives.

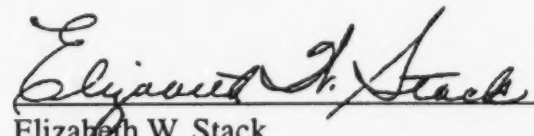
This report would also not have been possible without the gracious assistance of the program directors, parenting aides, and volunteers of the eight parenting programs reviewed. The dedication of these women and men in helping parents who are mentally retarded and in many cases in extending their workdays far into the night and weekends was remarkable across the programs. At each of the eight parenting programs, these individuals devoted considerable time from their busy schedules to accommodate our site visits and to share with us what they had learned about serving parents who were mentally retarded.

This evaluation study was funded by a grant from the New York State Developmental Disabilities Planning Council. Throughout the conduct of the review, the Commission has benefited from a discussion of the issues presented with the members of the Council.

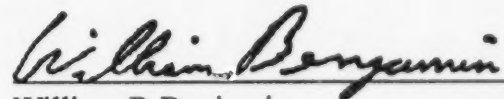
The findings, conclusions, and recommendations expressed in the report reflect the unanimous opinion of the Commission.



Clarence J. Sundram
Chairman



Elizabeth W. Stack
Commissioner



William P. Benjamin
Commissioner

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Staff Acknowledgments

Project Director

Nancy K. Ray, Ed.D.

Project Coordinator

Harriet Rubenstein, C.S.W.

Research and Statistical Analysis

Natalie J. Russo

Staff

Mindy T. Becker
Nancy D. Bell, A.C.S.W.
Katherine M. Bishop, M.S.
Elizabeth J. Chura
Mary C. Craven
Jacqueline García, M.S.W.
Loretta Goff, R.N., M.S.
Patricia W. Johnson, Esq.

Karen J. Myers, M.H.S.A.
Cheryl A. Ouimet, C.S.W.
Mark E. Rappaport, R.N., M.S.
Victoria L. Rinere, M.S., Ed.
Corinne Romanotto, C.S.W., M.S. Ed.
Laurie A. Trojnor
Victoria Zambardino, M.P.A.

Production Staff

Joyce A. Salazar
Gail P. Fetsko

Chapter I

Introduction

This report looks at lives of a special group of New York families—families with one or both parents known to have significant intellectual impairments and/or developmental disabilities. The Commission came to know more about these families through the conduct of an evaluation study, requested and funded by the New York State Developmental Disabilities Planning Council, which examined eight demonstration programs the Council had funded to serve parents with developmental disabilities.

Over the years, the Commission, and especially its regional Protection and Advocacy Offices, had intervened on behalf of a small number of parents with developmental disabilities. Through this study, the Commission has come to appreciate that parents with intellectual impairments and/or developmental disabilities are a diverse group of individuals. While many of the families share some common struggles in parenting their children, and especially in coping with incomes less than the established poverty level, as a group, they are characterized by their heterogeneity.

Most importantly, it did not usually appear that the parents' specific intellectual and developmental limitation was the only significant

The Commission has come to appreciate that parents with intellectual impairments and/or developmental disabilities are a diverse group of individuals.

factor influencing their capacity to parent their children. Like all parents, their motivation to parent, the training and experience they had with

parenting tasks and responsibilities, their other strengths and needs, and the presence of specific formal and informal supports in their lives were often equally, if not more, important factors influencing their ability to nurture and care for their children. At the same time, through the conduct of this study, the Commission has also

It did not usually appear that the parents' specific intellectual and developmental limitation was the only significant factor influencing their capacity to parent their children.

come to appreciate that intellectual impairments and other disabilities were often substantial handicaps for the parents studied as they attempted to fulfill their parenting responsibilities.

Over the course of this study, we were able to become acquainted with 54 of these families, and 25 of these families invited us into their homes for a visit. Yet, there is still much that we do not know about the quality of life for these parents and their children, particularly over the long term, as their children grow into adolescence and adulthood. Similarly, there is still much to learn about the support services from which these parents and their children will most benefit, and how these services should be provided and funded.

Thus, this is a preliminary report introducing some basic information about parents with significant intellectual impairments and/or developmental disabilities and the programs and services in their communities designed to assist

them and their children. What we have learned, however, has clearly indicated that providers of social programs serving families and children can no longer overlook the special needs of this significant and growing population of parents who require services in their communities.

It became apparent that most of the available literature was anecdotal in nature and that empirical studies focusing on the number of families headed by one or two parents with developmental disabilities have not been reported.

Literature Review

The Commission began its evaluation by studying available research and literature focusing on parents with developmental disabilities. As we pursued this objective, it became apparent that most of the available literature was anecdotal in nature and that empirical studies focusing on the number of families headed by one or two parents with developmental disabilities have not been reported. Although several articles have been published in recent years tracing parenting training programs for these families or the problems parents with mental retardation encounter in parenting, empirical needs assessment studies on significant samples of these families were sorely lacking.

One subset of studies reports on efforts to identify parents with developmental disabilities and to determine the well-being of their usually very young children. Feldman et. al. (1985), for example, reported on a small case study of 12 mothers who were mentally retarded and their two-year-old children. Although none of the children were diagnosed with disabilities at birth, the study found that the two-year-old children raised by the mothers were at high risk for developmen-

tal delays, especially in language. The research also found that the inability of a mother to care for an older child, as determined by child protective services, as well as the passivity of mothers, significantly correlated with the presence of developmental delays in the children.

Whitman et. al. (1987) reported on a community survey of parents who were mentally retarded. Relying on community agencies, they identified 280 families with one or more parents who were mentally retarded. These families had a total of 1,096 children. Their study, found that fewer than 15% of the parents had received help from schools or other agencies with child-rearing and parenting skills, although over one-fourth of the parents had at least one child removed from their custody.

One of the more interesting studies in this area was conducted by O'Neill (1985), who studied a small cohort of 19 children with normal or above-average intelligence who had a mentally retarded parent. Over half of the children studied displayed negative adaptations and behavior, including open rebellion, social adjustment problems, and impulse control problems. Another one-fourth of the children had taken over the parental role in the family with a subsequent lack of adult fulfillment.

Reports of parenting training programs generally assert positive outcomes for families participating in the training, but empirical evaluation data are not presented.

Reports of parenting training programs for mothers and fathers who are mentally retarded are more common in the literature. These reports focus on describing the curriculum of the

parenting programs with some information of the teaching interventions used. The reports generally assert positive outcomes for families participating in the training, but empirical evaluation data are not presented.

For example, Nanis and Scheer (1984) reported on a home-based training program, Project P.A.L.S. (Parents Are Learning Skills), sponsored by a local voluntary mental retardation agency in California since 1978. The project found that four problems characterized the families served: (1) lack of basic parenting skills; (2) parental social/emotional instability; (3) social isolation; and (4) inability to access available government entitlements and community resources. Based on their work with parents with developmental disabilities, the authors offered specific parenting training guidelines, including keeping verbal instructions simple, avoiding questions that only have yes/no answers, modeling the performance of tasks, and treating parents with respect and dignity.

Whitman et. al. (1989) reported on an alternative service delivery model for parents with mental retardation, which relied most heavily on interactional instruction for parents and children in a four-day-a-week early intervention school setting. Although the sponsors reported anecdotal successes, they noted that despite the provision of transportation, attendance was sporadic and fluctuated around 50%.

The Commission's review surfaced only one article which dealt with the ethical questions involved in serving parents who are mentally retarded.

In another report, Highway et. al. (1988) discussed the Positive Parenting Project in Brown County, Wisconsin. Opened in 1985, this program provides in-home, individualized, and intensive case management services for families.

In their report, they acknowledged the impediments of the parents' cognitive limitations in generalizing parenting concepts and skills, and they cited the limited social and "play" skills of the parents. The article concluded with a report of positive outcomes for children and parents who participated in the program, but empirical evaluation data were not presented.

One of the more useful parenting training guides was prepared by Bakley of San Diego University (1986). This guide provides a listing of 20 problems typically encountered in these families and offers successful teaching approaches. For example, in working with parents who may appear as unresponsive or as having a flat affect, the guide recommends activities that have high interactive potential. For helping mothers who misinterpret a baby's cries, the guide recommends a checklist of common reasons why babies cry, which mothers can reference.

Graves et. al. (1990) reported on a similar didactic teaching curriculum for parents with mental retardation. The curriculum includes eight basic goal areas (e. g., child development, addressing the child's basic needs, daily routines, etc.) and, in each area, specific behaviorally stated objectives are listed. For example, one objective under the goal area of daily routines is "to keep a housekeeping schedule with 90% accuracy."

The Commission's literature review surfaced only one article, Dennis Brodeur's "Parents with Mental Retardation and Developmental Disabilities: Ethical Issues in Parenting" (1990), which dealt comprehensively with the ethical questions involved in serving parents who are mentally retarded. While endorsing the strong legal and ethical presumption that biological parents should care for their own children, he cautioned that there are some indications that,

Review Methods

- ✓ Meetings with program directors
- ✓ Review of program proposals
- ✓ Review of program funding and staffing
- ✓ Two site visits to each program
- ✓ Record reviews and staff interviews for 41 enrolled families (initial sample)
- ✓ Modified Developmental Disability Profile of parents in 41 enrolled families (initial sample)
- ✓ Home visits to 25 enrolled families (second sample)

even in the best of circumstances, some parents with mental retardation will not be able to meet the child's long-range adolescent needs. Brodeur supported enriched early intervention programs for parents who are mentally retarded (before problems surface), but he qualified, "Children's long-term needs cannot be sacrificed for adults' short-term gains."

Methodology

Data collection for this study took many turns. As noted above, the Commission began by studying the relevant literature. Next, Commission staff met with the directors of the eight demonstration programs, funded by the New York State Developmental Disabilities Plan-

ning Council, to discuss their programs, their accomplishments, and the problems they have encountered. Of note, at the time of this meeting, most of the programs were funded for approximately one year, but most had been operational (i.e., serving families) for only about six months. Early telephone interviews with each of the program directors further helped the Commission to acquaint itself with the programs and their operations.

-Program Site Visits

Commission staff also made two on-site visits to programs, one in the fall of 1991 and one in the spring and summer of 1992. Both visits focused on obtaining a front-line perspective of the day-to-day operations of the programs and the families they served. On the initial visit, Commission staff spent several hours speaking with program staff and reviewing the program records of a sample of 41 of the 86 families enrolled in the eight programs. Program staff were also asked to complete a slightly modified version of the Developmental Disability Profile (DDP), the official needs assessment of the New York State Office of Mental Retardation and Developmental Disabilities, for each of the parents in the 41 families.

On the second visit, Commission staff visited homes of 25 enrolled families, accompanied by the parenting aide/volunteer assigned to the family. These 25 families included 12 families in the initial sample, plus 13 new families.¹ During the second site visit, Commission staff also met with the staff of the local departments of social services to obtain an understanding of how the programs interfaced with local child protective and preventive services.

¹ Although the Commission had hoped to make home visits to all 41 of the families in the initial sample, this was not possible. At the time of the follow-up visits, one of the eight programs had closed down operations, and staff of one other program steadfastly refused to allow any home visits. At the remaining six programs, there were other sampling changes, as some of the initial families had dropped out of the program, and some families did not want the Commission staff to visit.

Interview data with program staff and families, as well as record review and fiscal data, were collected on structured instruments.

-Other Activities

The Commission also visited three other agencies with special experience and expertise related to the needs of families with parents who are significantly intellectually limited or developmentally disabled. Two of these agencies, the Herkimer Association for Retarded Children and the Huntington Family Center, had been serving a significant group of families headed by parents with these disabilities for more than five years. The Commission also made a site visit to the Westchester Institute for Human Development (formerly called the Westchester Mental Retardation Institute). In the past several years, staff at the Institute had worked with local agencies serving parents with developmental disabilities, and they had prepared a video tape of several of these families in their homes.

Finally, the Commission requested written expenditure and budget information from the eight demonstration programs. In the summer of 1992, we also conducted structured telephone interviews with the directors of the seven operating demonstration programs to obtain a better understanding of their current funding sources and their plans and prospects for continued funding when their demonstration project grants from the New York State Developmental Disabilities Planning Council expired in 1993.

Limitations

Although these activities helped the Commission to learn much about families with parents who are significantly intellectually limited and/or developmentally disabled, they were not without their limitations. In particular, for many of the families studied and/or visited, there were

significant historical gaps in the program staff's clinical knowledge and records. Formal psychological assessments of the parents were conducted uniformly by only a few programs, and structured assessments of the parents' adaptive functioning in daily living and parenting skills were not regularly completed by any of the programs.

Social histories of the families were similarly incomplete, and in most cases, little was known of the parents' childhoods or historical encounters with child protective or preventive

Historical service profiles of the parents were so fragmentary that it was impossible to make any judgments about whether early intervention services had made a difference.

services (as children or as parents). At the time of the Commission's visits to the programs, nearly half of the families studied had one or more children who were living out of their homes due to allegations of neglect or abuse.² Staff at most of the programs visited knew little of these children or the incidents that had led to their removal.

Similarly, most of the programs had little information about the services that the families had accessed in the past, either as children or as adults, and as parents. With the notable exception of some parents who had been clients of the local mental retardation agency since they were youngsters, historical service profiles of the parents were so fragmentary that it was impossible to make any judgments about whether early intervention services had made a difference in their parenting abilities.

² Historically, almost half of the 54 families studied or visited (49%) had one or more children removed from their homes temporarily, due to allegations of abuse or neglect.

Finally, good recordkeeping and regular and descriptive progress notes were not strong features of the majority of the eight programs. Much of what was known about the families was not documented in charts, but verbally shared by paid staff and volunteers. These individuals had usually established close and personal relation-

ships with the families, and their accounts had the credibility of real life stories, with plentiful examples from their personal encounters. Nonetheless, the reader is advised to bear in mind that these reports were also subject to the vagaries of personal recollections and impressions.

Chapter II

The Parents and Their Families

As discussed in the previous chapter, during its initial site visits to the eight demonstration programs in the fall of 1991, the Commission obtained data on 41 families with parents who were intellectually limited or developmentally disabled. Approximately six months later, in the spring and summer of 1992, Commission staff made home visits to 25 families, 12 of whom were also included in the initial sample of 41 families.

As stated earlier, there were significant differences in the data collected during the two site visits to the programs, and in general, more comprehensive data were collected on the 41 families in the initial sample. Due to these differences in data collection, most of the data findings in this chapter pertain to the 41 families in the initial sample. Where data are available on both samples of families, they are presented discretely.

Overview

The parents served by the eight demonstration programs tended to be relatively young, and almost all of their children living at home were under the age of ten. Most of the families were small, and 41% were headed by single parents. The families studied and visited were also largely poor families, and many had lived or were now living in substandard housing.

For many of the parents, their own childhoods had been marked by abuse or neglect and/or out-of-home placements, and unfortunately, these histories followed many of the parents into

adulthood. Almost half of the families had had at least one child removed from their custody, at least temporarily, due to allegations of abuse or neglect, and histories of domestic violence and trouble with the law were common to approximately one-fourth of the families.

Although few of the parents had a physically handicapping condition, over one-third had a significant medical condition, 22% had a known alcohol or drug abuse problem, 20% had a diagnosed psychiatric condition, and over half had one or more reported "behavioral" problems, sometimes ascribed to their developmental disability, ranging from tantrumming to being verbally abusive or assaultive to others.

For many of the parents, their own childhoods had been marked by abuse or neglect and/or out-of-home placements, and unfortunately, these histories followed many of the parents into adulthood.

Program staff described almost all of the parents as mentally retarded, but they also characterized most of the parents as independent in most personal care daily living skills and as competent in basic adult literacy skills. In contrast, however, few of the parents demonstrated independence in many basic parenting skills, including childcare supervision, medical care follow-up, shopping for and cooking nutritionally balanced meals, providing appropriate discipline, and money management.

Edward and Charlene G.

Mr. and Mrs. G. met each other at the state institution where they both lived until they were 22. They have two children, Patrice, age 4, and Gerald, age 2. Mrs. G. also has a 20-year-old daughter from a previous marriage, who visits often and helps around the house.

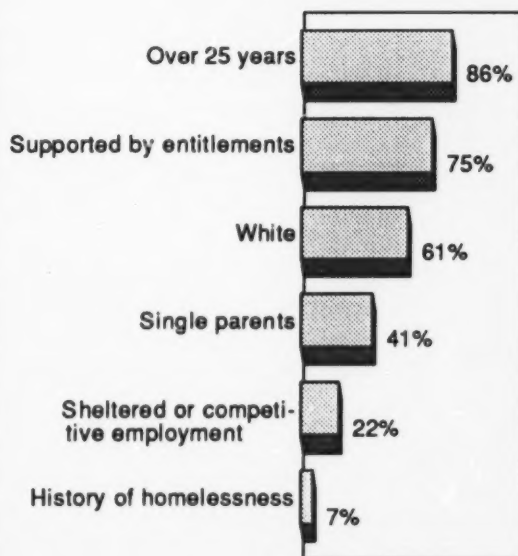
This family lives in a residential neighborhood in a very clean three-bedroom apartment. They have all the modern conveniences, including a microwave, several television sets, a VCR, a dishwasher, and a coffee maker.

Both Mr. and Mrs. G. are mildly mentally retarded, and Mr. G. has an ambulation problem and uses a cane. Mrs. G. works full-time at a nursing home, where Mr. G. also volunteers two mornings a week. They are very supportive of one another and share in caregiving for their children and in all the household chores. They can become easily overwhelmed, especially when one parent has to care for both children at the same time. In the evenings, Mr. G. prepares dinner for the family, and the family often visits other extended family members who live in the community and provide considerable support.

Mr. and Mrs. G. have been enrolled in the parenting program for slightly more than one year, and the volunteer, who spends about eight hours a week in their home, reported that the family is doing well. Although Patrice is learning disabled, the volunteer stated that she is a smart and outgoing child who enjoys painting and drawing and likes to be the center of attention. Her younger brother, Gerald, has been diagnosed as mildly mentally retarded, with a slight speech impediment, but he is reportedly doing very well at the preschool program that he is attending. The volunteer described Gerald as a happy, well-adjusted boy.

The volunteer told the Commission that Mr. and Mrs. G. can well manage most of the household chores, cooking balanced meals and attending to the children's medical and dental needs. He is focusing his time with the parents in encouraging them to be comfortable with and a little less protective of the children, particularly in allowing the children to play with appropriate toys, crayons, coloring books, etc. This is very difficult for Mr. and Mrs. G. who fear that if something happened, their children would be taken away.

Figure 1: Profile of Parents*
(N = 41 Families)



*Yes ratings were given to two-parent families if one or both parents met the indicator.

Demographics

Parents in more than half of the 41 families (61%) were Caucasian; 29% were African-American; 5% were Hispanic; and 5% were of another ethnic origin, including one Native American family (Figure 1).

Most of the parents were young, but not very young. Three-fourths were between the ages of 25 and 40, with only 12% under 25 and only 9% over 40.³ In contrast, almost all of the 66 children who were living at home with the 41 families at the time of the Commission's visit were *very young*. Seventy percent (70%) were younger than 5 years old, and 40% were 2 years old or younger. Only 9% of the children living at home were over 10 years of age.

Virtually all of the families lived on the edge economically. In only 3 of the 41 families (7%) were one or both parents competitively employed at least some time each week; in another six families (15%), one or both parents worked some time each week in a sheltered or supported work setting. Three-fourths of the families, however, were supported by public entitlements, including aid to dependent families, SSI, and food stamps.

Almost all of the families (regardless of size) sustained themselves on less than \$900/month. Staff of the parenting programs further described 18 of the 41 families (44%) as living in significant poverty, and 3 of the 41 families (7%) had a known history of homelessness. With the exception of the 10 families who lived in supportive apartments or enriched foster care homes subsidized by funding grants from the Office of Mental Retardation and Developmental Disabilities, housing arrangements were also marginal for most of the families. Although parenting programs had helped many of the families move to more suitable apartments or homes, most families continued to live in cramped arrangements or in housing that was difficult to heat or needed maintenance work.

Family Structure

Of the 41 families in the initial sample, 41% were single-parent families, but the majority (59%) had at least two "parenting" adults in the household. Fifteen (15) of the 24 two-adult families (63%) were married couples. The remaining two-adult families represented relationships that had spanned at least one year, and several of these couples had been together for four or more years.

³ Program staff could not provide the current ages of 3 of the 65 adults (5%) in the 41 sample families.

As in most American families, women assumed the dominant parenting role in more than three-fourths of these families. All but 1 of the 17 single-parent families were headed by women, and in the two-adult families, it was most common for the mother to stay at home and provide most of the child care, while fathers, stepfathers, or other male companions were much more likely to spend considerable time outside the home, working or engaged in other activities not related to parenting. In total, fathers, stepfathers, or male companions played an active parenting role in only 22% of the 41 families.

While only 3 of the 41 families (7%) lived with relatives, program staff reported that the majority of the 41 families (95%) had some extended family members (grandparents, siblings) living in the local area. This statistic may be somewhat misleading, however. Interviews clarified that for many families, their relatives also lived on marginal incomes and had few

resources to share. In other cases, extended family members made demands on the families' already limited financial and housing resources.

Family Size

With the exception of 1 of the 41 families, who was expecting its first child shortly, all of the families had at least one child. In total, these families had 96 children, or an average of 2.3 children per family. Twelve (29%) had only one child; 12 (29%) had two; and 16 (39%) had three or more, including 7 families with four or more children.

Almost one out of every two of the families studied, however, had at one time lost the custody, at least temporarily, of one or more of their children, usually due to allegations of abuse or neglect (Figure 2). At the time of the Commission's review, 17 of the 41 families (41%) had at least one of their children living

**Figure 2: Out-of-Home Placements
of Children by Family
(N = 41 Families)**

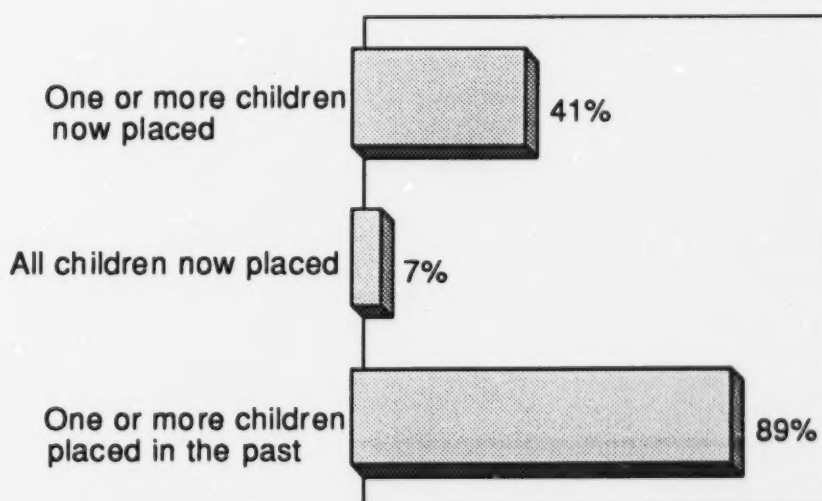
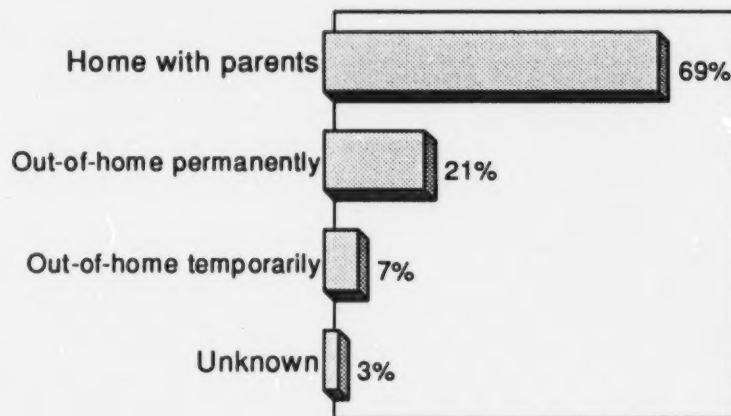


Figure 3: Children's Place of Residence
(N = 96 Children)*



*Reflects status of the 41 families in the Commission's initial sample at the time of the fall 1991 visits.

out-of-home, and three of the families had recently lost custody of all of their children. From another perspective, 30 of the 96 children (31%) represented in the sample were not currently living with their parents (Figure 3).

For ten families, their children had been in an out-of-home placement for several years. Some of these children had been formally adopted (often by an extended family member), and in other cases, reuniting the children with their natural parents was not an active goal. In contrast, program staff reported that for nine families, reuniting one or more of their children was an important priority and the parents' main motivation for enrolling in the program.⁴

Of the 66 children who were living at home with their families at the time of the Commission's review, almost half (49%) had no siblings at home, with a sample average of only 1.4 children per family *living at home*. Thirty percent (30%) of the families had two children living at

home, and only 21% of the families had three or more children.

Medical, Mental Health, and Physical Limitations

One or both parents in approximately one-third of the families had medical conditions which required ongoing treatment and monitoring (Figure 4). Common conditions included respiratory disorders and conditions (15%), seizure disorders (7%), cardiovascular conditions (5%), gastrointestinal conditions (5%), neoplastic diseases (5%), and other neurological conditions (2%).

One or both parents in 20% of the families also had a concomitant psychiatric diagnosis and either currently or at some time in the recent past had received mental health services. And, one or both parents in nearly one-fourth of the families (22%) were known to have a drug or alcohol abuse problem.

⁴ For 2 of the 17 families with children placed out-of-home, efforts were focused on reuniting one child, but there were no active efforts to reunite other children who were in out-of-home placements.

Marie L.

Ms. L. is a 25-year-old single mother of two boys, 4-year-old Alan and 7-month-old Michael. As a child, Ms. L. was abused, and she has a history of unstable relationships, domestic violence, homelessness, and poverty.

Prior to enrolling in the parenting program, Ms. L. had been living with an abusive boyfriend in a building that program staff described as needing to be condemned, and both of her children had been placed out-of-home. Alan had been placed in foster care due to physical abuse by his father; and later, when Michael was born prematurely, Ms. L. voluntarily placed him in foster care due to his extensive medical problems.

An initial service of the parenting program was to relocate Ms. L. in her own small, but much more appropriate, two-bedroom apartment. Subsequently, the staff worked with local child protective services to arrange home visits for Alan. Several months later, Ms. L. regained custody of Alan. Presently, Ms. L. has overnight visits with Michael, and the goal is for him to return home within six months.

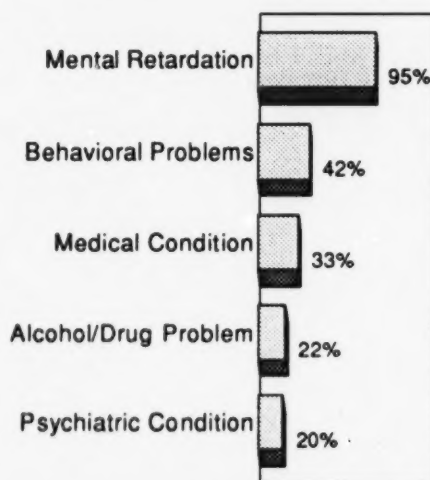
Alan has a speech impairment and attends a daily preschool program, where he is learning to put words together and talk in sentences. Ms. L. keeps busy getting Alan ready for his preschool program, cleaning the house, preparing meals, and making weekly visits to her other son, Michael.

Ms. L. has been enrolled in the parenting program for about 15 months. The senior companion visits Ms. L. twice weekly for at least four hours a day and assists in housekeeping, shopping, parenting skills, and appropriate discipline. She also provides transportation to medical appointments, follow-up on medical care treatment, and coordination with Alan's preschool program.

Since enrolling in the program, Ms. L. has made much progress. She has learned to maintain the apartment, which was clean and appropriately decorated at the time of the Commission's visit. Both children are lactose intolerant, and Ms. L. has also learned recipes for dairy-free meals and desserts. All agree that Ms. L. has made the greatest progress in parenting Alan. She reads him stories; she spends time with him playing outside, coloring, painting, and drawing; and she helps him to speak correctly and in full sentences.

Ms. L. is very proud of her accomplishments, but she remarked that it is stressful to manage her time with her sons. Ms. L. told the Commission that the best part of being a parent was "sharing time with the children," and the difficult part was "taking them to all the doctors' appointments." She also stated that she wanted a transition period with Michael before regaining custody, so she can get used to having him home for longer periods of time.

Figure 4: Concomitant Problems of Parents*
(N = 41 Families)



*Yes ratings were given to two-parent families if one or both parents met the indicator.

Reflective of their medical problems, parents in 34% of the families were also taking prescribed medications on a regular basis for medical conditions (20%), mental health symptoms (10%), or seizure disorders (5%).⁵ According to program staff, all but one of the parents taking prescribed medications were capable of managing their own medications and taking them as prescribed by their doctors.

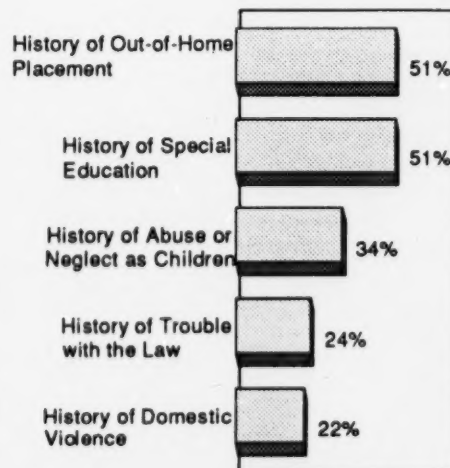
In contrast to the prevalence of medical conditions, few of the parents in the 41 families had any significant physical disabilities. No parent in any of the 41 families was truly non-ambulatory or had a significant hearing loss. One parent in 2 of the 41 families (5%) had some difficulty walking and used a cane, and one parent in 4 of the 41 families (10%) had a significant vision impairment, which was not correctable with glasses.

Significant "behavioral" problems were also associated with parents in over half of the families. Reportedly, one or both parents in 42% of the families sometimes have behavioral "tantrums" or emotional outbursts, and one or both parents in 37% of the families are sometimes verbally or gesturally abusive toward others. In some cases, program staff directly ascribed these behavioral problems to the parents' developmental disabilities. More seriously, program staff reported that one or both parents in 15% of the families have physically assaulted others, and one or both parents in 10% of the families have intentionally damaged their own or others' property.

Social Histories

Through interviews with the staff of the parenting programs, Commission staff attempted to obtain a social history of the 41 families. As

Figure 5: Social Histories of the Parents*
(N = 41 Families)



*Yes ratings were given to two-parent families if one or both parents met the indicator.

⁵ One of the parents who reportedly had a seizure disorder was not receiving anticonvulsant medications at the time of the Commission's review.

Pam T.

Ms. T. is a 27-year-old mentally retarded mother of a 1-year-old daughter, Alison, a 2-year-old son, Richie, and a 4-year-old son, Bobby. Only Alison now lives with Ms. T., as both of her older brothers were placed in foster care some time ago. Little is known about why Bobby was placed in foster care, but the parenting program has been assisting Ms. T. in her efforts to reunite with Bobby, who is scheduled to begin having supervised home visits.

Ms. T.'s second son, Richie, was placed in foster care shortly after birth when Ms. T. lived at a homeless shelter. Richie was hurt when he fell at the shelter, and the shelter staff did not feel that Ms. T. was capable of caring for him. There are no plans for reuniting Richie and his mother, and he is in the process of being adopted by his foster family.

Ms. T. has been involved with the parenting program since it opened and just before the Commission's visit, she and Alison had moved into a large one-bedroom supportive apartment operated by the program's sponsoring agency. On the day of the Commission's visit, the apartment was spotless, well-maintained, nicely decorated, and nicely furnished.

Ms. T. spends her days taking care of Alison, cleaning the apartment zealously, socializing with other mothers in her apartment building, attending parenting classes and appointments, and taking the baby to an infant stimulation program two and a half days each week. On the day of the Commission's visit, Alison was dressed in a cute sundress with frilly socks and sneakers, and her wisps of hair were clipped on top of her head. Ms. T. proudly told Commission staff that her daughter will be christened on the coming Sunday, showing off Alison's christening dress, hat, shoes, and socks.

Ms. T.'s senior volunteer makes home visits twice each week, staying for about four hours each visit. Over the past few weeks, the volunteer has concentrated on building a trusting relationship with Ms. T. and evaluating her strengths and needs. The volunteer reported that Ms. T. has cognitive limitations which affect her language, memory, and overall judgement skills, but that she is very accepting of assistance and training in cooking, parenting, and child care. The volunteer added that she believes Ms. T. and her daughter benefit greatly from the parenting program.

Ms. T. also believes that the program has been very helpful, and with its help, she hopes to soon have her 4-year-old son, Bobby, at home with her, too.

noted in Chapter I, at most programs staff acknowledged that their historical information for many families was sketchy or vague. Even with these limitations, which tended to undercount problems and difficulties, the information obtained indicated that many of these parents had difficult childhoods and that many have continued to have significant problems as adults.

One or both parents in half of the 41 families (51%) had a history of out-of-home placements (Figure 5). And, for one-third of the families (34%), one or both parents were known to have been abused or neglected as children.

Given the high reported incidence of mental retardation among the parents, it was somewhat surprising that one or both parents in only half of the 41 families (51%) were known to have a history of special education. This figure may be reflective of program staff's limited knowledge of the parents' educational backgrounds. Or, it may indicate that many of the parents may not have had the benefit of an educational program tailored to their special needs.

Domestic violence, often associated with alcohol or drug abuse, was reported as a current or recent problem for 9 of the 41 families (22%). In many of these families, domestic violence problems had directly led to the involvement of local child protective services.

One or both parents in one-fourth of the families (24%) had a recent history of trouble with the law (20%) and/or actual incarceration (12%). As with the incidence of domestic violence, the reported criminal activity was often

secondary to alcohol and drug abuse, and it usually did not involve serious crimes against persons. The most common criminal charges included driving while intoxicated and disorderly conduct.

Cognitive Abilities

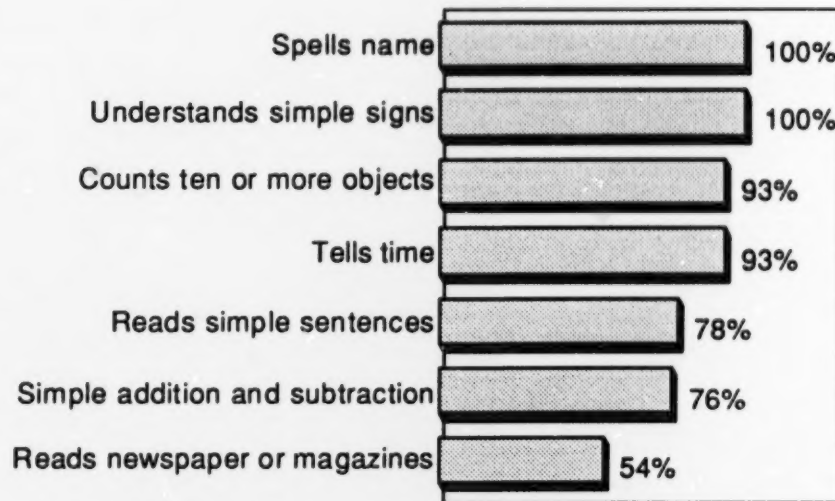
Based on the Developmental Disability Profiles completed by staff in the eight parenting programs, one or both parents in 95% of the 41 families were mentally retarded. From another perspective, at least one parent in 22% of the 41 families was *not* identified as being mentally retarded.⁶ In almost all cases, program staff indicated that the parents judged to be mentally retarded were mildly retarded; one or both parents in only 10% of the families were described as moderately retarded.

Notwithstanding these reports, staff of the parenting programs gave at least one parent in most of the 41 families competent ratings in most basic adult literacy skills (Figure 6).

- ☐ One or both parents in 54% of the families could read and comprehend a newspaper or magazine article.
- ☐ One or both parents in 76% of the families could do simple addition and subtraction.
- ☐ One or both parents in 78% of the families could read and comprehend simple sentences.
- ☐ One or both parents in 93% of the families could tell time to the nearest five minutes.

⁶ Of note, these Developmental Disability Profile (DDP) findings conflicted with the verbal interview reports of program directors to Commission staff. In their initial verbal reports, the program directors indicated that one or both parents in only 63% of the families were mentally retarded. In choosing to rely on the DDP data, the Commission considered that program directors had more time to check with records and other sources in completing DDP surveys for the parents. Nonetheless, it should be noted that many of the parents had not had a formal psychological assessment in many years, and diagnostic reports by the program directors may not be valid.

Figure 6: Literacy Skills of Parents*
(N = 41 Families)



*Yes ratings were given to two-parent families if one or both parents met the indicator.

- ☐ One or both parents in 93% of the families could count ten or more objects.
- ☐ One or both parents in 100% of the families could understand simple signs, such as "Exit" or "Restroom."
- ☐ One or both parents in 100% of the families could spell their first and last names.

This high level of basic cognitive competence among the families was partially accounted for by the two-adult families, where one parent's skills compensated for the limitations of the other. In other cases, however, program staff's judgments of the parents' literacy skills simply seemed to exceed what might be expected based on the staff's reports of parents' level of mental retardation.

Daily Living Skills

Reflective of the parents' cognitive abilities, staff of the parenting programs reported that at

least one parent in the vast majority of the 41 families had sufficient competency to perform most of the skills of daily living independently. For example, program staff reported that one or both parents in 75% of the families were able to perform basic self-care and hygiene tasks (e.g., showering, toothbrushing, hair care, and dressing appropriately) independently. Parents in only 10% of the remaining families were judged as actually needing supervision in helping them do these tasks. In the other 15% of the families, program staff reported that parents were capable of performing these tasks independently, but they chose not to.

Program staff also rated at least one parent in the vast majority of the families as independently performing other basic tasks, like using the telephone (90%), making beds (81%), and preparing meals that do not involve cooking (85%). In all cases, the parents reported as not performing these tasks independently were assessed as being capable of the tasks, but unwilling.

ing to do them. Parents in over three-fourths of the families (81%) were also assessed as capable of using public transportation independently.

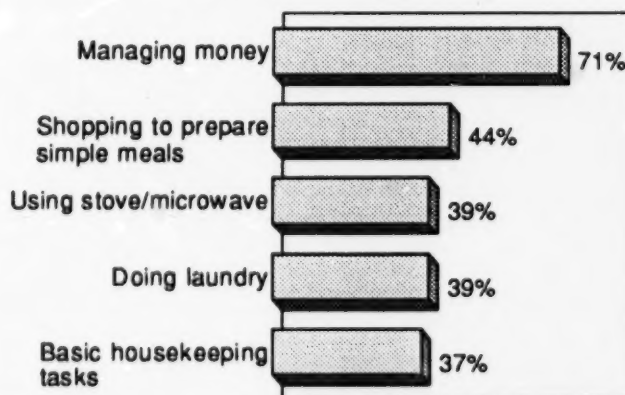
On some housekeeping tasks, however, a greater percentage of the parents were judged not to be independent (Figure 7). For example, program staff reported that in over one-third of the families, there was not at least one parent who could independently do the laundry (39%), use a stove or microwave (39%), shop adequately to prepare simple meals (44%), or perform basic housecleaning tasks (37%). Even in these skill areas, however, the reported failure to perform the tasks independently was not always attributed to lacking ability. Program staff indicated that about half of these parents could perform these tasks, but that without outside supervision or assistance, they usually chose not to.

In rating parents as capable of doing a task but choosing not to, program staff uniformly reported personal knowledge of the parents' capability. Nonetheless, caution should be exercised in directly attributing these ratings to unmotivated or disinterested parents. Although

many parents had skills to do particular tasks, for most, their cognitive limitations placed real restrictions on their ability to organize time and keep track of what needed to be done. These issues, rather than poor motivation, may have been the significant factors in their poor performance of these daily living skills.

Poor money management skills were clearly the most common problem among the families studied. In over half of the families (71%), there was reportedly no parent capable of managing money independently. As virtually all of these families lived on subsistence or poverty level incomes, this finding, too, requires a cautious interpretation. It was not always easy to distinguish clearly those families who lacked an adult with basic money management skills from families in which parents simply struggled in managing money on an austerity budget. Program staff did report, however, that in nearly one-fourth of the families (24%), there was no adult who could perform simple addition or subtraction, which clearly would interfere with their capacity to budget their money appropriately.

Figure 7: Tasks Not Performed
Independently by Parents*
(N = 41 Families)



*"Not independent" ratings were assigned to two-parent families only if both parents were not independent on the task.

Tina M. and Steve E.

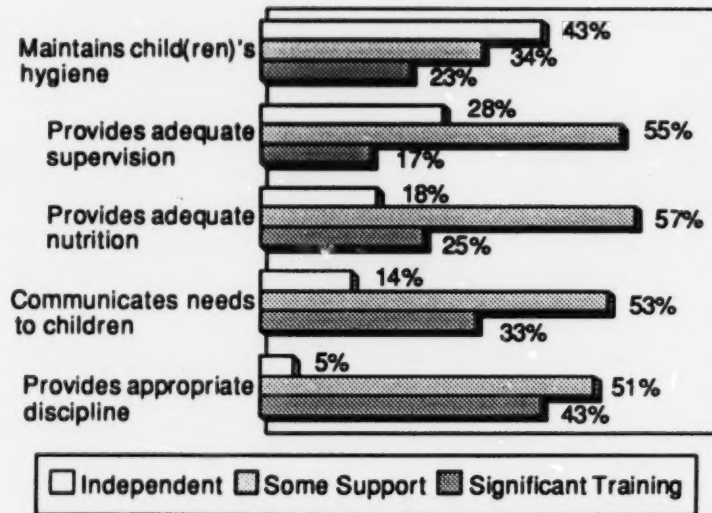
Ms. M. is a 42-year-old woman with mild mental retardation and a moderate anxiety problem marked by a decreased frustration tolerance. She lives with her fiancé, Mr. E., and their 3-year-old son, Paul. Ms. M. also has significant health problems, including hypertension, elevated cholesterol, and an escalating weight problem. She also takes prescribed medications for her ulcers and nervous stomach.

Reportedly, Ms. M. and Mr. E. have been engaged for 14 years, but they have delayed their marriage, as they fear Ms. M. would lose her Social Security benefits since Mr. E. is employed full-time. Ms. M., who has always been overweight, had denied that she was pregnant, until it became clear to everyone. Initially, she had decided to give the baby up for adoption, but changed her mind after Paul was placed in foster care with Mr. E.'s sister. After a two-year wait, in 1992, Paul moved home with his parents. Since moving home, Paul, who has some behavioral problems, but no identified developmental disabilities, has been attending an early intervention program.

This family lives in a clean three-bedroom apartment. Ms. M. has good housekeeping and cooking skills, shops independently, and has good personal hygiene. Ms. M.'s greater difficulties center on her parenting skills. According to the parenting program staff, Ms. M. is very afraid her son will be taken away from her and consequently, she compensates by overfeeding Paul to keep him happy and by being overprotective. These fears also contribute to Ms. M.'s reluctance to discipline Paul, as she is afraid that if she does discipline Paul, he will not love her.

Ms. M.'s volunteer, who spends approximately 8 hours a week in the home, is helping Ms. M. develop appropriate discipline skills with Paul, including limit setting and anger management, as well as preparing proper meals, toilet training, and handling emergencies. The volunteer reported that Mr. E. is very supportive of Ms. M., and that Ms. M. is highly motivated and very excited about finally being able to care for her son. The volunteer added that she hopes Ms. M. will become more comfortable in her parenting role and more willing to work on keeping her relationship with Mr. E. Although the volunteer was optimistic that these objectives would be met, she also stated that this family would likely need substantial support and services for years to come, at least until Paul is a fairly independent adolescent.

Figure 8: Level of Parenting Skills*
(N = 41 Families)



*In two-parent families, ratings reflect performance of most capable parent.

Parenting Skills

In sharp contrast with the parents' generally high competence and independence ratings in basic adult literacy and personal daily living skills, staff of the parenting programs gave most of the parents in the 41 families "dependent" ratings in basic parenting skills (Figure 8). Follow-up interviews with the second sample of 25 families with whom Commission staff visited at home also confirmed these initial reports.

Based on reports of the parenting program staff, most of the 41 families in the Commission's initial sample required some support or significant training in most basic areas of parenting skills. In each of the areas listed below, program staff were asked to rate families as "independent," "needing some support," or "requiring significant training."

- ❑ Parents in one-fourth (25%) of the families were rated as requiring significant training *in providing adequate nutrition to their children*, and parents in an

additional 57% were rated as needing some support in this area.

- ❑ Parents in 43% of the families were rated as requiring significant training *in disciplining their children appropriately*, and parents in an additional 51% were rated as needing some support in this area.
- ❑ Parents in 33% of the families were rated as requiring significant training *in communicating their wishes or needs to their children*, and parents in an additional 53% were rated as needing some support in this area.
- ❑ Parents in 17% of the families were rated as requiring significant training *in ensuring adequate supervision for their children*, and parents in an additional 55% were rated as needing some support in this area.
- ❑ Parents in 23% of the families were rated as requiring significant training *in attending to their children's personal hy-*

Gerard and Dorothy R.

Mr. and Mrs. R., ages 32 and 36, have been together for a number of years and married for three. They have four children. Peter and Eric, 9 and 10 years old, are from Mrs. R.'s previous relationship. The two youngest, 3-year-old Billy and 15-month-old Mary, are Mr. and Mrs. R.'s children. This family of six survives on \$850/month, plus food stamps.

Mrs. R. is mildly mentally retarded and visually impaired, and she has a history of alcohol abuse. She was raised in foster care, and as a young adult, she was homeless for periods of time. Mr. R. is also intellectually limited, but he suffers more apparently from depression and alcoholism. His alcoholism has led to serious problems with the law, including a jail term for a felony assault. For about a year and a half prior to the Commission's visit, subsequent to a serious drug overdose, Mr. R. has been enrolled in alcoholism treatment.

The older boys are diagnosed as having an attention deficit hyperactivity disorder, and they have serious problems at home and at school. Both boys are difficult for the parents to supervise and discipline, and they have been receiving mental health services for years. About five years ago, Mr. and Mrs. R. lost custody of the boys for a period of time as a result of a house fire set when the boys were playing with matches during the day, while the parents were sleeping.

Three-year-old Billy has a seizure disorder, but no other known disabilities. He will enroll in Head Start or another day care program next year. Mary has shown some early signs of developmental delay in sitting, balance, walking, and drinking from a cup, but she is reportedly making great progress in an early intervention program.

Mr. and Mrs. R. are long-term clients of the local Association for Retarded Children, and they enrolled in the parenting program as soon as it opened. The program provides 15 hours of services each week, including daily weekday home visits. The parenting aide assists with transportation to medical appointments, household chores, shopping, and contacts with the children's school programs.

Mr. and Mrs. R. are very committed to the parenting program, and Mrs. R. will often call her parenting aide several times a day. The aide told the Commission that she is focusing her attention on helping Mrs. R. appreciate the value of letting her children play with toys and taking her youngest out of the playpen. The program also hopes to move this family into a supportive apartment, which will make them eligible for increased SSI payments and ensure more daily assistance in parenting.

Program staff were cautiously optimistic about the family's ability to stay together. The staff added, however, that this family has been receiving services for many years, and they will likely require continued support and assistance even after their children are grown.

giene needs, and parents in an additional 34% were rated as needing some support in this area.

Comparable findings were obtained during the home visits to the 25 families. For example, parent aides and volunteers assessed 92% of these 25 families as needing help in general parenting skills, 88% as needing help in ensuring appropriate discipline of the children, and 80% as needing help with basic child care. During home visits, parent aides and volunteers reported that most of the 25 families also had other parenting assistance needs.

- ☐ Over half of the 25 families (56%) needed help *in ensuring arrangements for and attendance at medical care appointments* for themselves and their children.
- ☐ Over three-fourths of the 25 families (80%) needed help *in finding appropriate recreational activities* for their children.
- ☐ Over two-thirds of the 25 families (68%) needed help *in shopping for food or other basic clothing items*.
- ☐ Forty-four percent of the families with school-age children needed help *in communicating with children's teachers*, and 48% needed help *in assisting school-age children with their homework*.

The Parents Speak Out

A more personal perspective of the parenting experience came from the parents themselves. When making home visits to the 25 families, Commission staff asked the parents, "What was the best part of being a parent?" As illustrated in the parents' comments below, most of the parents answered simply and eloquently that their joy in parenting came from loving and caring for their children.

Taking care of my children, playing with them, teaching them.

Loving [my son], watching him sleep.

Sharing time with my children.

Everything, my whole life revolves around [my son]. I want to give him a better life.

Taking the children to the park.

Being responsible for the children and preparing the proper foods.

Everything, being a family and having a lot of responsibilities.

On the flip side of the coin, the parents' comments on the difficult parts of being a parent evidenced an equally honest appraisal of their frustrations, fears, and insecurities.

Making sure my child is okay and safe, watching her, making sure she is not sick.

Knowing he's getting older, and it will be harder to parent.

When the kids get sick, [I am] not sure what to do.

Everything, having kids is the most difficult; getting the kids to listen and not letting the kids or my husband get to me.

In the evening, when I'm alone with all four kids at home, trying to feed them, get them ready for bed, and take care of the [infant] twins.

The 24-hours-a-day taking care of them, especially all the doctors' appointments.

It's hard to keep up with them; discipline is hard. They won't share. It is hard for my husband.

Having to repeat myself and having to hit the children.

Trying to make [my son] behave. I'm afraid he will love his aunt more than me. I'm also afraid he will be taken away.

I find it hard to be patient. I don't like to get up early. [My daughter] is bad sometimes. [My son] likes to cry.

As reflected in these comments, the parents with mental retardation enrolled in the parenting programs shared many of the mixed feelings of all parents. They spoke freely of their love of their children and how dear their children were to them. They also voiced common frustrations about the full-time job of parenting, with its

pleasant and less pleasant tasks and its rewarding and unrewarding moments.

A striking feature of the comments, however, was the parents' perceptiveness of their limitations and fears. In visiting with the families, Commission staff rarely met parents who did not explicitly reference their difficulties and limitations and their awareness that these problems placed them in ongoing jeopardy of losing the custody of their children. The parents' acknowledgment that their job would become increasingly difficult as their children grew past toddlerhood and entered school, was particularly noteworthy.

Chapter III

The Children and Their Well-Being

Demographic, clinical, adaptive behavior, and school performance data were collected on the children living at home in the initial sample of 41 families. In addition, program staff were asked a series of questions related to the general well-being and protection of these children. Limited information was available on the 30 children of these families who were not currently in their custody.

Data collected on the children of the 25 families in the second sample were considerably less comprehensive. For these children, Commission staff did not collect demographic, clinical, and social history data, although we did gather information related to their general well-being and protection from immediate harm and neglect.

Due to these differences in data collection, the data findings in this chapter primarily relate to the 66 children living with the 41 families in the initial sample. Where data were available on the children in the second sample, they are presented separately.

Overview

The vast majority of the children in these families, who were in their parents' custody at the time of the Commission's visit, were 10 years old or younger, and nearly half (49%) were 3 years old or younger. A high percentage of these children, especially those over 2, have been identified as having at least one disability or limitation, ranging from mental retardation to learning disabilities to emotional disorders to physical handicaps.

Although a majority of these children have come to the attention of their local departments of social services, often due to a past allegation of abuse or neglect, reports of the program staff indicated that most are now doing fairly well. For example, most receive nutritious meals, appropriate medical and dental care, proper attention to their dress and hygiene, and adequate supervision and discipline.

Notwithstanding these reports, on many basic indicators of custodial care, protection from harm, school performance, and adaptive behavior, approximately one-fifth of the children evidenced significant problems. At the time of the Commission's review, 26% of the 66 children living at home with the 41 families were on the rolls of their local child protective/preventive services, and 64% of the children had been on these rolls at one point in their childhood. Difficulties in getting to school appropriately dressed and groomed, keeping up with their school work, and making and keeping friends, as well as unspecified "behavioral" problems, were especially common among the children.

Demographics

Sixty (60) of the 66 children (91%) living with their parents in the 41 families were 10 or younger, and 70% were under 5. Two-thirds of the children were boys, and 65% were white (Figure 9).

By comparison, the 30 children of these parents who were not presently in their custody tended to be older (43%, 5 or older) and, predominantly girls (77%). Approximately one-

Carol N.

Ms. N., who carries a diagnosis of borderline mental retardation, is a 38-year-old mother of four children. Ms. N. and her mother are both alcoholics, and reportedly, Ms. N. suffered from fetal alcohol syndrome.

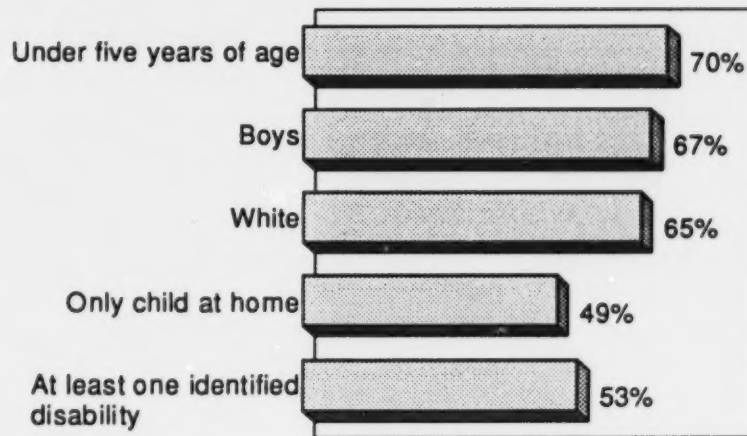
Ms. N. was court-ordered to the parenting program by Probation after serving jail time for a criminal child abuse charge. Ms. N. reported that she was joining the program in an effort to regain the custody of her four children.

At the time of the Commission's review, Ms. N. had been enrolled in the parenting program for about seven months, and she was still being followed by Probation and monitored by Child Protective Services. Recently, the court had allowed Ms. N. to resume custody of two of her children, her 18-year-old son Ron and her 6-year-old daughter Michelle. Both of these children have spent most of their childhood with Ms. N.'s sister. Ms. N.'s two other children remain in foster care. To keep her children, Ms. N. agreed to stay in the parenting program and to live in a supportive apartment operated by the parenting program's sponsoring agency.

Ms. N. receives 10-15 hours of service each week from the parenting program; she sporadically attends the weekly parenting class; and she works in a sheltered workshop. Ms. N. receives alcoholism counseling, as well. She is relatively independent in all personal hygiene and grooming skills, and she can cook and maintain her apartment. Ms. N.'s parenting aide spends much of her time helping Ms. N. develop more positive parenting skills and better money management skills and habits. According to the parenting program staff, Ms. N. frequently spends her money frivolously and does not have enough to cover the family's basic needs.

Over the past few months, Ms. N.'s two older children living at home have been doing relatively well. Program staff are assisting Ron with college applications. He is described as a bright, hard-working boy, who has been working at McDonald's since age 15. Michelle does not have any serious problems at school or with other children, although she often arrives late to school because Ms. N. has difficulty getting her ready on time. Staff also reported that they are providing regular monitoring to ensure that Ms. N. appropriately supervises Michelle and serves appropriate meals.

**Figure 9: Profile of the
Children at Home
(N = 66 Children)**



fourth of these children (27%) had been removed from their parents' custody at birth, presumably either voluntarily or on the grounds of "anticipatory neglect." Another 10% of these children had been removed before their second birthday, and in total 43% of these 30 children were known to have been removed from their parent's custody before their sixth birthday. (For 9 of these 30 children, or 30%, the age at which they had been initially removed from their parents' custody was not known.)

Eight of the 30 children (27%) who were not in the custody of their parents at the time of the Commission's visit had been adopted by other families (often by an extended family member). Termination of parental rights was pending for another four of these children. For 14 of these children (47%), steps were not underway to terminate parental rights, and for 9 of these 14 children, parenting program staff reported active efforts to reunite the child with his/her natural parents. (Parenting program staff were unaware of the status of the remaining four children.)

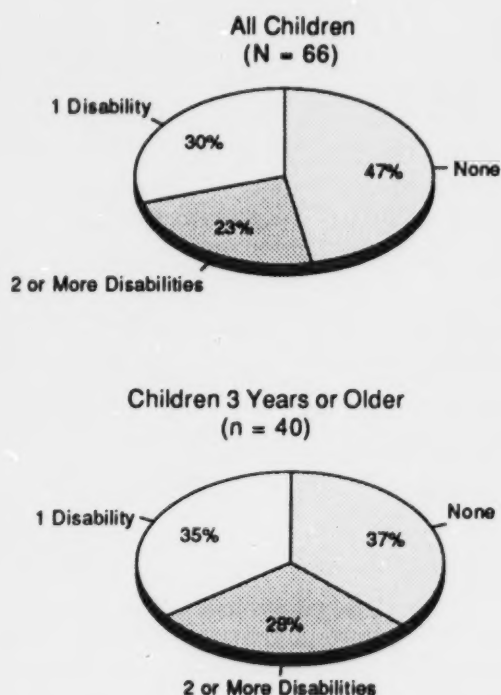
Clinical Profile

Thirty-five (35) of the 66 children (53%) who were living at home in the 41 families had at least one known disability or limitation, and 15 of the children (23%) had two or more known disabilities or limitations (Figure 10). The most commonly reported disabilities included mental retardation (24%), learning disabilities (21%), and conduct or attention deficit hyperactivity disorders (11%). Hearing and speech impairments (6%), seizure disorders (3%), blindness (3%), and autism (3%) were considerably less common.

Data analysis further showed that the percentage of children with identified disabilities increased with the children's age.

- ❑ Only 38% of the children 2 years of age or younger ($n = 26$) had an identified disability.
- ❑ In contrast, 63% of the children 3 years of age or older ($n = 40$) had an identified disability.

Figure 10: Disabilities of Children at Home



Although disability data were not available from the parenting program staff for 17 of the 30 children not in their parents' custody, data related to the other children placed out-of-home indicated that a lower percentage of these children (31%) had a known disability or limitation.

Basic Well-Being

During its initial site visits to the parenting programs, Commission staff asked the program staff a series of basic "yes-no" questions related to the general well-being of the 66 children living at home with the 41 families studied. Program staff responses indicated that most of the children experienced no regular problems related to these basic custodial care and protection from harm issues. At the same time, however, the responses indicated that almost two-thirds of the children (64%) had some involvement with their local departments of social ser-

vices and that basic custodial care and protection from harm problems persisted for about one-fourth of these children (Figure 11).

- ☐ Half of the children (48%) had been identified as a possible victim of an allegation(s) of abuse or neglect, and 23% had been the victim of a known *indicated* child protective services report of abuse or neglect.
- ☐ One-fifth of the children (21%) reportedly did not receive appropriate preventive medical care or needed ongoing medical treatment for a chronic health condition, including prescribed medications, and 24% reportedly did not receive appropriate dental care.
- ☐ Almost one-fourth of the children (23%) reportedly did not receive adequately nutritious meals; and 18% did not have adequate clothing.
- ☐ One-fifth of the children (21%) reportedly were sometimes left unsupervised and/or their parents did not always know their whereabouts.

Subsequently, Commission staff asked the parenting aides or volunteers working with the 25 families in its second sample a set of similar questions, querying the general well-being of the children. Although focusing on similar issues, these two sets of questions were phrased differently, and most critically, for the second sample of families, program staff qualified their answers more specifically in relating "recent" problems and the frequency of these problems. In these interviews, staff were asked to indicate if the particular jeopardy or problem had ever occurred and if so, if it had occurred one to three times in the past six months, four to six times in the past six months, or seven or more times in the past six months. Additionally, in the second survey, one answer or rating was recorded for the family, rather than a separate rating for each child.

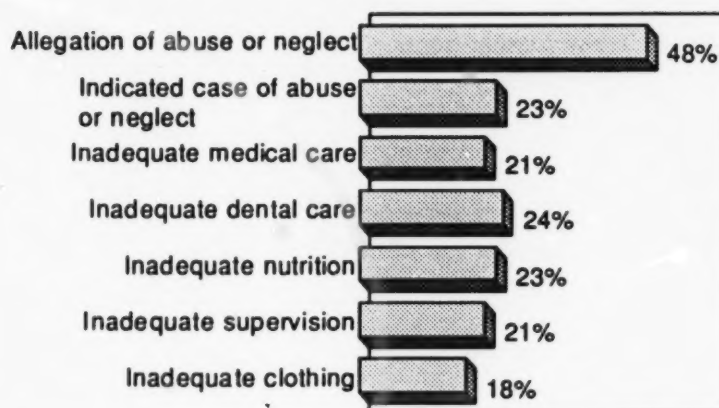
Results of the second survey were comparable with those from the first survey, confirming that the majority of the families usually provided for their children's basic protection and custodial care needs. Recent and recurring parenting limitations in these areas, however, were common to approximately one-third of the 25 families (Figure 12).

- ❑ Children in 28% of the families were judged to have been at risk of emotional or physical harm four or more times in the past six months; children in an additional 16% of the families were judged to have been at risk one to three times.
- ❑ Parents of children in 40% of the families reportedly used inappropriate strategies to discipline their children four or more times in the past six months; parents in an additional 16% of the families reportedly used inappropriate disciplinary strategies one to three times.
- ❑ The basic nutritional needs of children in 20% of the 25 families were reportedly not met four or more times in the past six

months; these needs were not met for children in an additional 20% of the families one to three times in the past six months.

- ❑ Parental supervision of the children in 20% of the families was judged to have been inadequate four or more times in the past six months; for children in an additional 28% of the families, such supervision was judged to have been inadequate one to three times in the past six months.
- ❑ Children in 16% of the families were reportedly physically or sexually abused or neglected four or more times in the past six months (no reports one to three times).
- ❑ Children in 12% of the families did not receive appropriate medical care (including prescribed medications) four or more times in the past six months; children in an additional 4% of the families did not receive needed care one to three times in the past six months.

**Figure 11: Safety and Well-Being
of the Children at Home**
(N = 66 Children)



Nancy and Drew S.

Mr. and Mrs. S. have been married for four years, and both are developmentally disabled. They live with their 2-year-old son Greg, in a residential neighborhood, where several of their relatives also live.

Mr. S., who works evenings as a custodian at a local supermarket, takes primary responsibility for parenting Greg and appears to be the spokesperson for the couple. Mr. S. told Commission staff that the best part about being a parent was "the challenge of it," and that the most difficult parts were "getting Greg dressed for school and getting him to go to sleep at night."

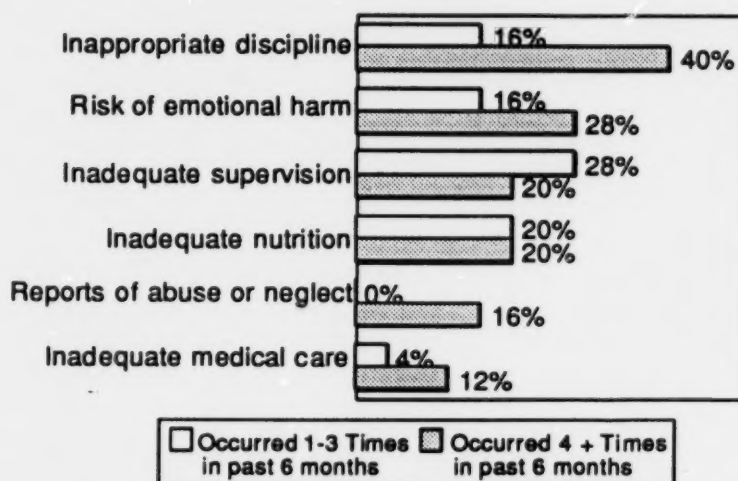
Mrs. S., who was described by the parenting program staff as moody and unpredictable, stays home and shares in caring for Greg with Mr. S.'s help. The parenting program volunteer stated that Mr. and Mrs. S. have difficulty managing Greg's problem behaviors and that he has recently been enrolled in an early intervention program to address these behaviors, as well as his signs of developmental delay.

Child Preventive Services had been involved with this family in the past, but it recently dropped the family from its rolls, reportedly due to the improvement the family had shown in caring for their apartment. On the day of the Commission's announced visit, however, the family's two-bedroom apartment was not in good shape. Countertops and floors were sticky and dirty; there were many flies throughout; many of the furnishings were soiled and broken; and the sheets on the baby's crib were filthy.

The parenting program volunteer spends four hours each week teaching Mr. and Mrs. S. how to provide well-balanced meals and how to help Greg play with toys and practice the skills he is learning in his early intervention program. The parenting program volunteer noted that the family has benefitted from the training offered, but that she remains concerned that Greg is not always supervised appropriately.

During the Commission's home visit, Mrs. S. took care of Greg's needs, but she did not always seem to know where he was. Many times he wandered onto the front porch and out of eyesight; and Mrs. S. seemed unaware that he could have quickly darted out into the street. Many of Mr. and Mrs. S.'s nieces and nephews were also continually running in and out of the house, playing or cooing over Greg, creating a very chaotic environment. Mrs. S. made no effort to supervise or discipline the children. Finally, Mr. S. took control of the situation.

**Figure 12: Safety and Well-Being
of Children in Families Visited
(N = 25 Families)**



School Performance

For the 34 children living at home with the 41 families in the initial sample and attending some sort of school program, Commission staff obtained some information on their school performance. Eleven (11) of these 34 children were enrolled in preschool programs (often an early childhood development program or Head Start), and 23 were enrolled in grade school programs.⁷

As reported by the staff of the parenting programs, a significant minority of the 34 children attending school programs had some problems with school attendance and/or in arriving at school properly attired and groomed and with adequate supplies (Figure 13).

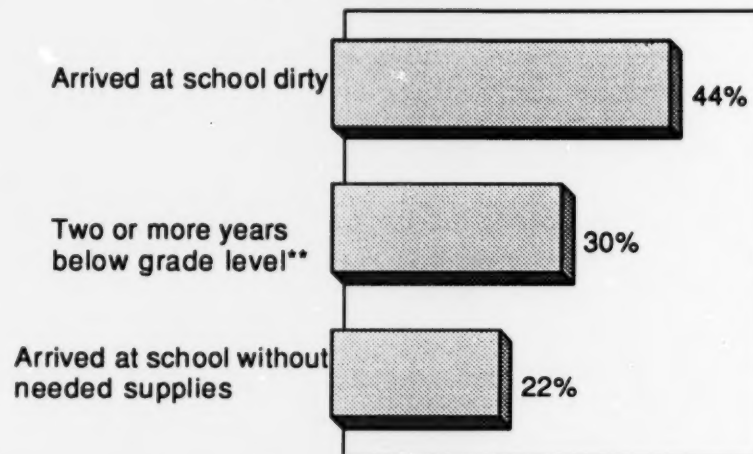
- ❑ One-fifth of these children had problems with school truancy (15%) and/or tardiness (18%).

- ❑ Nearly half of these children (44%) arrived at school periodically in dirty clothing and/or with markedly poor personal hygiene.
- ❑ One-fifth of these children (22%) arrived at school without necessary school supplies (e.g., pencils, paper, crayons, etc.).

Program staff also reported that many of the 23 children who were enrolled in public grade school programs were having some academic problems. Nearly half of these children (43%) had a Committee on Special Education (CSE) designation, and 30% were two or more years below grade level in their reading and/or math achievement levels. Additionally, staff of the parenting programs indicated that for 43% of these children, "school problems" were an ongoing issue. Sometimes these problems related

⁷ Of note, only 11 of the 29 children (38%) in the sample who were preschool age were enrolled in preschool or other day care programs.

Figure 13: Problems Encountered in School
(n = 34 Children)*



*The subsample of 34 children includes the 11 children enrolled in preschool programs and the 23 children enrolled in grade school programs.

**Half (53%) of 13 children 8 years of age or older were two or more years below grade level.

to the children's academic work, but often they related to the children's appearance, attendance, and behavior in the classroom.

Of note, parents or parenting aides or volunteers reportedly provided homework assistance for approximately half of the children (48%) enrolled in grade school, and another 26% were specifically identified as receiving remedial assistance in school.

Maladaptive Behavior

Initially, the Commission had hoped to obtain ratings on adaptive and maladaptive behaviors for all 66 children living at home with the 41 families. Unfortunately, however, for many of the very young children, most of the measures developed to assess adaptive and maladaptive behavior were not relevant. Thus, although staff of the parenting programs generally indicated

that 68% of the children had achieved major developmental milestones of infancy and early childhood, data on more specific indicators of the children's developmental accomplishments and difficulties were obtained only for the 23 children in the sample who were 5 years old or older.⁸ These children represented only 35% of the 66 children.

Data on these 23 older children (ages 5 - 19) indicated that few manifested serious maladaptive behaviors in the past three months. For example, fewer than 10% of the children had assaulted an adult (4%), set fires (0%), engaged in self-injurious behaviors (9%), been involved with the police (4%) or used illegal drugs or alcohol (4%). In addition, relatively few of the children had engaged in the more common childhood misdeeds of hitting another child (17%) or sibling (35%) or parent (13%). Despite these reports on specific indicators, however,

⁸ Over half of the children who were identified as not achieving basic developmental milestones of infancy and early childhood were also identified as being mentally retarded or seriously hearing impaired.

program staff reported that 43% of the children had displayed unspecified "behavioral problems" three or more times in the past three months.

Adaptive Behaviors

With respect to positive adaptive behaviors, the findings were more mixed; on a number of the indicators, these findings were also confounded by missing information for a significant minority of the children. As shown in Figure 14, in the vast majority of these indicators, fewer than half of the children were awarded "usually" ratings, but most of the remaining children received "sometimes" ratings, and fewer than 20% of the children received "rarely" ratings.

These findings suggest that the vast majority of the children had the capability to demonstrate the assessed social behaviors, self-care skills,

and household chores, but they were not consistently doing so. This observation suggests that the less than optimal scores of the children may be more attributable to irregular parental supervision, monitoring, or assistance rather than an absolute skill deficit.

The one exception to this general rule centered on indicators related to the children's likelihood to socialize with children in other families (Figure 15). Nearly half of the school-age children (44%) rarely had friends over to their house to play; and 26% of the children rarely went to another child's house to play. Almost one-fifth of the school-age children (17%) also rarely developed and maintained friendships with other children, and only 13% were reported to be involved in any extracurricular activities at school. In total, 52% of the school-age children in the sample received "rarely" ratings on one or more of the above social indicators.

Figure 14: Adaptive Behaviors of the Children
(n = 23)*

	<i>Usually</i>	<i>Sometimes</i>	<i>Rarely</i>
<i>Self-Care Skills</i>			
☐ independently completes daily hygiene tasks	35%	35%	17%
☐ dresses self appropriately	44%	39%	9%
☐ picks up toys, clothing, etc.	52%	30%	9%
<i>Socialization Skills</i>			
☐ displays good table manners	35%	17%	13%
☐ develops and maintains friendships with other children	57%	9%	17%
☐ develops and maintains relationships with adults	52%	9%	17%
☐ has friends over to the house	26%	17%	44%
☐ goes to other children's houses to play	44%	13%	26%

*The subsample of 23 children includes only children five years of age and older.

Maryann N.

Ms. N. is a 38-year-old single mother of an 8-year-old daughter, Diane. Ms. N. is employed as a housekeeper part-time, and she attends a sheltered workshop in the afternoon. Ms. N. picks up her daughter at 6:30 p.m. on weekdays from her day care program, where she goes after her special education class.

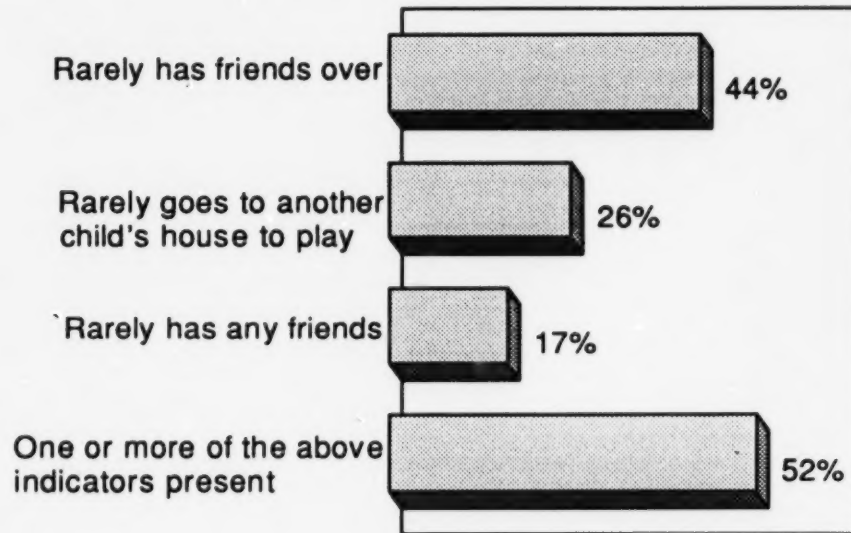
Ms. N. and her daughter live in a one-bedroom apartment. Diane is moderately mentally retarded and has a secondary diagnosis of autism. According to staff, she has difficulty with structure, has temper tantrums, and runs away. During the Commission's visit, Ms. N. appeared uncomfortable, and almost all of her comments about her daughter were negative. During the interview, Ms. N. focused on Diane's incapacity to listen, her inability to clean up after she plays, and her problems with bed wetting. She also mentioned how Diane took her moisturizing cream, used it on her doll's hair, and created a mess. During this time, Diane appeared to comprehend what her mother was saying, and she sat with her head down, playing with her dolls. During the visit, Ms. N. and Diane never made eye or physical contact with one another.

According to the staff, Ms. N. is committed to the parenting program and is cooperative and receptive to suggestions. They noted that Ms. N. is able to meet Diane's nutritional needs and to provide adequate supervision and medical care, but that she has more difficulty in using appropriate discipline strategies and in interacting with Diane positively. According to program staff, Ms. N. also needs to learn how to complete specific tasks without constant reinforcement and prompting.

The parenting program staff visit with Ms. N. eight hours each week, and they work on housekeeping, cooking, and budgeting skills. They are also trying to help Ms. N. in interacting more positively with Diane, in helping her with her homework, and in providing recreational activities.

When asked by Commission staff to identify the best parts of being a mother, Ms. N. did not respond, but later she reported that the stressful parts included her inability to control Diane's behaviors, having to pick up after her all the time, and constantly reminding her not to curse or jump on the furniture. Parenting program staff were cautiously optimistic about the ability of the family to stay together, but they remarked that Diane may become more difficult for her mother to manage as she becomes older.

Figure 15: Isolation of the Children
(n = 23 Children)*



*The subsample of 23 children includes only children five years of age and older.

Collectively, these data findings confirmed the reports of the parenting programs' directors that an outstanding need of many of the families related to the provision of recreational and leisure activities, which would help lessen their social isolation and also provide the needed socialization opportunities for their children. Staff of the programs specifically cited this

unmet need in association with 29 of the 66 children (44%) in the sample. It was also cited by most program directors as an essential service, and one that was not offered as often as they would like, largely due to the considerable resource expense of providing transportation for the families and their children to participate in planned recreational events.

Chapter IV

Services Received by the Families

At the time of the Commission's review, all of the families studied were enrolled in a parenting program funded in part or in full with a grant from the NYS Developmental Disabilities Plan-

The eight programs were more dissimilar than similar in their models of service delivery and resources.

ning Council. The Council had anticipated that each of these programs would use a common model of service delivery, which relied extensively on the use of volunteers for the provision of services to the families and which focused on in-home parenting training and support services.⁹

As the Commission visited the eight programs, however, it soon became apparent that they were more dissimilar than similar in their models of service delivery and resources. These differences significantly influenced the services received by the families studied, regardless of the families' needs.

As discussed in this chapter, the services the families actually received were dependent on many variables. It mattered which of the eight parenting programs served the family and what resources and services it offered or arranged through other community programs; it mattered

what services the parent(s) agreed to accept; and finally, and often in this order of priority, it mattered what services the family needed.

Program Models Differed

The programs differed most apparently in the extent to which they relied on volunteers versus paid parenting aides as the backbone of their on-site service delivery to families. Two programs relied exclusively on paid staff and did not use any volunteers as in-home family workers; two others used some volunteers, but relied on paid staff.

The four remaining programs relied primarily on volunteers, but one of these programs closed its operations at the end of the second funding year, and another remained very small, serving only five families. A third program which relied upon volunteers had also enrolled approximately half the families it served in its enriched foster care program which essentially ensured 24-hour supervision to these families, in addition to the assistance and training provided by the volunteers. Although these operating programs which relied heavily on volunteers spoke eloquently of their dedication and services, it was clear that reliance on volunteers was perceived by most programs as too limiting of their flexibility and capability in serving enrolled families.

⁹ Most volunteers were senior citizens enrolled in the NYS Office of Mental Retardation and Developmental Disabilities "Senior Companion Program." This program enlists the assistance of senior citizens with low incomes (less than 125% of the poverty level) to work with persons with developmental disabilities. Senior companions are paid \$2.35/hour for their services.

John W.

Mr. W. and his 6-year-old son, Steven, live together in a supportive apartment sponsored by the local Association for Retarded Children, which also sponsors the parenting program. Mr. W., who is 54 years old, is mildly mentally retarded, and he is considered a high risk for coronary disease due to his high cholesterol. In addition to caring for Steven, Mr. W. works four days a week at the sponsoring agency's sheltered workshop.

Mr. W. has not always cared for Steven. Several years ago, Mr. W.'s girlfriend (and Steven's mother) moved out-of-state, taking Steven with her. Ultimately, Steven's mother lost custody of Steven due to neglect charges. After nine months of negotiating, Mr. W. was awarded custody of Steven, contingent on his living in a supportive apartment and receiving services from the local Association for Retarded Children.

According to all involved with Mr. W. and Steven, they are doing well with the supports that they receive. Mr. W. attends a weekly parenting class sponsored by the ARC, and he receives 10-12 hours a week of in-home support and training in parenting, domestic skills, and medication administration. Mr. W. is grateful for the help he receives, and he acknowledges that it makes the difference in allowing him to raise his son.

Steven is doing well in first grade. He is described as a friendly and lovable child, who gets along well with other children and adults. He has been receiving mental health services for approximately one year to help him express his feelings, particularly about his mother.

At the time of the review, Mr. W. and Steven had been living together and doing well for approximately one and a half years. Although program staff remarked at the progress that has been made, they also affirmed that Mr. W. will continue to need significant support and assistance until Steven is grown.

Some programs were also able to access the service resources of their sponsoring agency and other community agencies much more extensively than others. This networking with other programs had significant implications for both the diversity and intensity of service provision that the parenting programs were able to arrange for their enrolled families. For example, three of the eight programs had accessed agency supportive housing or enriched foster care programs for some of their families; some had accessed Medicaid-funded case management programs; and still others had ensured substantial home health aide services (up to 40 hours weekly) for a few of their families.

Funding Differences

The fiscal resources supporting the eight parenting programs varied considerably, in part

because the size of the Council's awards varied, but more substantially because some programs were able to rely more extensively than

Networking with other programs had significant implications for both the diversity and intensity of service provision that the parenting programs were able to arrange for their enrolled families.

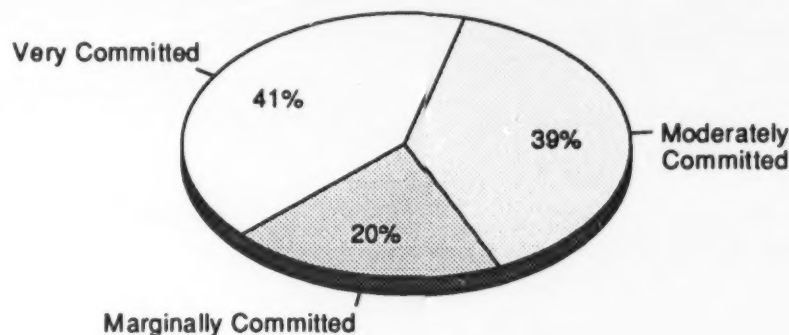
others on supplemental funding sources. Although none of the eight programs relied exclusively on their Developmental Disabilities Planning Council award, for two programs approximately 80% of their direct parenting program services were reportedly funded by the award.

Figure 16: Total and Per Family Funding by Parenting Program*

<i>Program</i>	<i>Total Parenting Program Funding</i>	<i>DDPC Grant Award</i>	<i>Total Families Enrolled</i>	<i>Per Family Funding</i>
Orleans County ARC	\$126,180	\$70,000	27	\$ 4,670
Sinergia, Inc.	\$104,000	\$84,000	18	\$ 5,770
Young Adult Institute	\$ 96,429	\$75,000	9	\$10,710
Heritage Centers	\$ 55,555	\$50,000	5	\$ 8,890
Community Services for the Developmentally Disabled, Inc.	\$ 71,429	\$50,000	11	\$ 6,490
Chautauqua ARC	\$ 71,000	\$50,000	10	\$ 7,100
The Task Force for Child Protection, Inc.	\$ 56,143	\$40,000	10	\$ 5,610

* All funding information is based on program self-reports for fiscal year 1991-92 with the exception of Heritage Centers, which is based on a 15-month period. Enrollment information is based on self-reports of enrolled families as of fall 1991. Funding information for Ulster County ARC is not included, as this program closed in December 1991.

Figure 17: Program Commitment of Families
(N = 41 Families)



Average Drop-out to Enrollment
Rate Across All Programs = 40%

In contrast, at two other programs, only 55% and 61% of the funding for their direct parenting services, respectively, came from the award. The most common and substantial other funding source of these programs was the NYS Office of Mental Retardation and Developmental Disabilities, which offered grants ranging from just over \$10,000 to over \$50,000 to half of the eight programs.

As shown in Figure 16, total annual resource allocations of the eight programs in 1992 ranged from \$56,143 to \$126,180, and per family resources (based on the number of enrolled families in the fall of 1991) ranged from less than \$5,000 per family at one program to more than \$8,000 per family at two other programs.

Family Interest Also Influences Services

At each of the eight programs, program staff also emphasized that services, except for the minority of families who are court-remanded, are voluntary, and families do not always choose

to accept all the services that they are offered. For example, Commission staff heard reports of families where parents declined enrollment in day programs or sheltered workshops, refused alcoholism services, and turned down more suitable housing and added supports in a supportive apartment program.

When asked to rate the commitment of the families to the parenting program, program staff reported that 41% of the 41 families in the Commission's initial sample were "very committed" (Figure 17). Another 39% of the families were rated as "moderately committed," while 20% of the families were described as "marginally committed" or likely to quit at any time. These reports were reflective of the actual drop-out rates of the eight programs. In the past year, the eight programs reported that 36 families had dropped out, reflecting a drop-out rate of approximately 40% of their average ongoing program enrollment.

Only 9 of the 41 families in the Commission's initial sample were bound by any legal or other contract to stay involved with the program.

Seven of these nine families had been court-remanded to the parenting program, while two other families were required to stay involved in the parenting program as a condition of their residence in a supportive apartment.

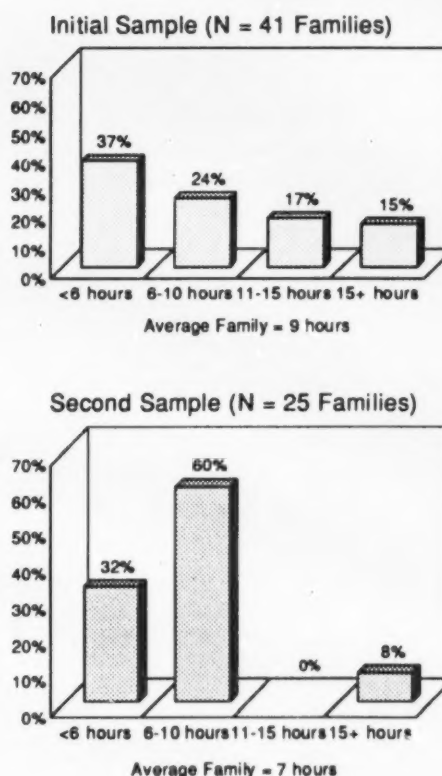
It is also important to note that at the time of the Commission's initial site visit in the fall of 1991, only one of the eight programs had been operational for more than three years, five had been operational just under two years, and two had been operational less than one year. The newness of several of the programs affected their service delivery, both because many programs were still "finding their way" and most were still struggling to find the most effective means of intervening with less motivated families.

Intensity of Service Provision

The Commission found that the intensity of service provision varied substantially among the families studied and that, as a general rule, many factors apart from the families' needs influenced how intensely they were served. At the time of the Commission's first site visit in the fall of 1991, the average family in the initial sample of 41 families received nine hours of service each week. Actual service provision per family ranged from less than one hour weekly to over 15 hours weekly (Figure 18).

Most critically, five of the families in the initial sample of 41 families and four of the families in the second sample of 25 families were living in some form of supportive housing funded by the parenting program's sponsoring agency. These families received services from three of the eight parenting programs, each of which provided supportive housing to one-fourth to one-half of their enrolled families. These supportive housing programs included traditional supportive apartments with staff supervision 10-20 hours weekly, enriched family foster care homes where the foster family helped to

Figure 18: Service Intensity to Families



care for both the parent(s) and the child(ren), and one larger apartment program, which also had some provisions for congregate meals.

It is difficult to even compare the services provided to these families in supportive housing arrangements with the other families in the sample. They were much more richly served; they almost invariably had daily staff contact; and program staff/foster family involvement with their children was sometimes so significant that they appeared to be "surrogate" parents.

On the other end of the spectrum, more than one-third (37%) of the 41 families in the Commission's initial sample received five or fewer hours of service weekly. About one-fourth (24%) reportedly received 6-10 hours of service

Lucy F.

Ms. F. is 29 years old and the mother of four children. She dropped out of her special education high school program at age 19, but in the past year she has returned to an adult education program.

According to parenting program staff, Ms. F. is mildly mentally retarded, and she has a history of child abuse, domestic violence, and unstable relationships. Some time ago, Ms. F.'s three older children were placed in foster care, reportedly due to allegations of sexual abuse. The alleged perpetrator was Mr. B., Ms. F.'s long-standing boyfriend and the father of her fourth child, John.

Ms. F. and Mr. B. share a small apartment with John who was 18 months old at the time of the Commission's review. Mr. B. works part-time as a painter, while Ms. F. spends her days taking care of John, visiting friends, doing household chores, and assisting Mr. B. with his painting business.

John is not mentally disabled, and he has met the developmental benchmarks for his age. Due to respiratory problems, however, he requires the use of a vaporizer, regular suctioning of his bronchial passages, and ongoing medical observation and treatment.

Ms. F. has been enrolled in the parenting program since November 1990, but according to program staff, she is only marginally committed to receiving services and is sometimes not home when the parenting aide visits and often resists specific recommendations. Mr. B. reportedly does not participate at all. At the time of the Commission's review, Ms. F. had refused home-based services, but she periodically attended the parenting class and received staff assistance in coordinating health care services and case management contacts from local child preventive services.

Ms. F. initially enrolled in the parenting program with the expectation that it would assist her in regaining the custody of her other three children. Shortly after her enrollment, however, the county decided to terminate her parental rights and allow her three older children to be adopted.

Parenting program staff stated that Ms. F. is a high-risk parent who needs much more intensive services than she is willing to accept. In particular, staff are concerned that she may not always ensure appropriate nutrition for John and that her discipline techniques, which include physical punishment, may place John at risk of physical abuse. In addition, staff remain uncomfortable about Mr. B.'s reported history of sexually abusing her other three children.

weekly, and the remaining families (32%) reportedly received more than 10 hours of service weekly, including six families (15%) who reportedly received more than 15 hours of service weekly.¹⁰

Service intensity was similar, but somewhat less intensive for the 25 families the Commission visited in the spring of 1992. About one-third of these families (32%) received five or fewer hours of service weekly; 60% received between 6-10 hours of service weekly; and 8% received more than 15 hours of service weekly.

Virtually all of the families in both the initial sample of 41 families and the second sample of 25 families received at least weekly home visits from paid or volunteer parenting aides (90% and 96%, respectively), and almost three-fourths of the families in both samples were visited at least twice weekly by program staff.

Only one program preset the number of home visits to one visit weekly. At the other programs, the number of home visits was predicated on a number of other factors, including the program's resources, the family's willingness to have frequent visitors, and the crisis status of the family in any one particular week. In addition, families who were dependent on the parenting program for transportation services for shopping and medical and other appointments inevitably had more frequent contact with program staff.

Nature of Service Provision

Virtually all of the families received specific assistance in parenting, as well as parenting training. Program staff also reported that 85% of the families received case management-type assistance, as the parent aide or volunteer helped the family to coordinate services with other agencies and to solve emerging family problems.

During the Commission's fall 1991 visit, program staff also provided a more descriptive picture of the assistance that they rendered to the 41 families in the initial sample (Figure 19).

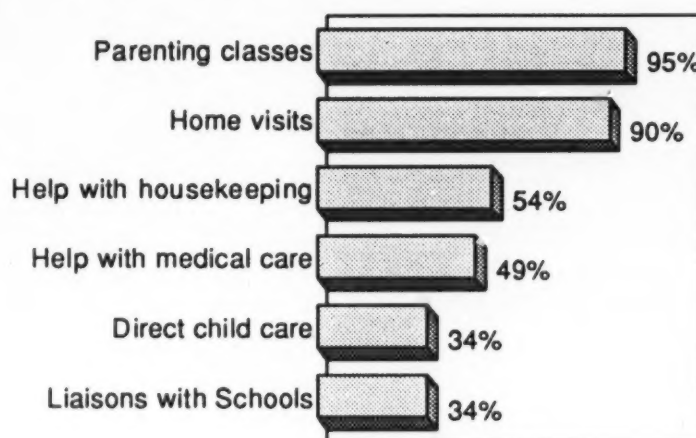
- ☐ Over half of the families received assistance and training in specific household (54%) and other daily living chores (59%).
- ☐ Program staff transported and accompanied nearly half of the parents (49%) to medical, dental, and mental health appointments.
- ☐ One-third of the families (34%) received direct child care services from the parent aide/volunteer.
- ☐ Program staff/volunteers served as liaisons between the parents and school teachers and other school personnel for children in 34% of the families.

During home visits to the 25 families in the second sample, paid aides and volunteers were even more specific in relating what services and training they provided.

- ☐ Over two-thirds of the families (68%) received help with housekeeping, and nearly half received help in cooking (48%), shopping (44%), and money management (44%).
- ☐ Almost half of the families (48%) received help in ensuring medical care follow-up, 40% were transported to medical appointments, and 32% received help in managing medications.
- ☐ Program staff assisted 68% of the families in arranging some social/recreational activities, and they helped parents in 64% of the families relate to one another or other significant adults in their lives.

¹⁰ Program staff of one program were unable to provide information on the intensity of service provision for 3 of the 41 families in the initial sample. On average, this program reported providing 4 hours of service weekly per family.

Figure 19: Services Provided by Parenting Programs
(N = 41 Families)



As reflected in the above listings of services, all programs provided some in-home parenting training, but providing direct assistance with the tasks of daily living, as well as case management services, consumed the largest percentage of most programs' resources. While parenting aides and volunteers differed from home health aides or homemakers in that they usually worked side-by-side with the parents in doing tasks, rather than just doing the tasks for the parents, their direct assistance with specific tasks essential to parenting could not be overlooked.

Parenting Classes

Each of the eight programs also offered structured off-site parenting training classes. These sessions covered a wide range of topics (Figure 20), and the curriculum at each of the eight programs appeared to be tailor-made. With the exception of two programs where parenting classes met biweekly or monthly, these classes met weekly, and they usually combined about an hour of class with a social activity.

In the Commission's initial sample, 32% of the families attended these classes, and in the second sample, 72% of the families attended.

Figure 20: Topics for Parent Training Classes
(N = 8 Programs)

- ☐ Positive communication with children
- ☐ Social relationships
- ☐ Ups and downs of motherhood
- ☐ Your child and school
- ☐ Bedtimes and children
- ☐ Child development
- ☐ Self-esteem
- ☐ Health care
- ☐ Birth control
- ☐ AIDS and prevention
- ☐ Alcoholism and treatment
- ☐ Child abuse and neglect
- ☐ Good nutrition
- ☐ Basic cooking skills

Attendance for many families, however, was not regular, with most families missing at least one class a month and many missing two classes a month.

Many reasons were given for the irregular attendance at the parenting classes, ranging from problems in transportation and child care to limited parental interest, but most program staff candidly acknowledged that these classes just did not work well for most of their families. In general, many staff felt that the classes met the social and peer support needs of the parents more effectively than they taught specific skills. Both the diversity of the families' needs and abilities and their common cognitive limitations made group instruction difficult and sometimes less than successful. Most programs also found that combining the parenting class with a meal or dessert snack, as well as offering child care services, helped attendance.

Other Program Services Targeted Toward the Children

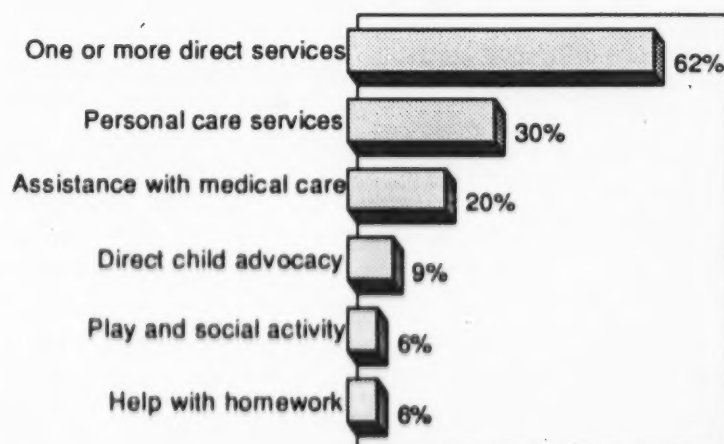
Seven of the eight programs had an explicit mission to serve the entire family, both the

parents and the children. At the one remaining program, program staff stated that while they may refer children to other services, their primary service mission was to meet the needs of the parents.

The philosophy of this latter program, however, was not typical. Although all programs recognized that the best way they could help the children was by helping the parents be better parents, most programs had a conscious focus on addressing the primary needs of the children to the extent that they were able.

The Commission obtained the most discrete data on services to the 66 children living at home with the 41 families in its initial sample. According to program staff reports, direct services were provided to 62% of these 66 children (Figure 21). By far the most frequently rendered services related to basic custodial and medical care services. Programs reported directly assisting 30% of the 66 children in maintaining their personal care and hygiene, and 20% of the children in ensuring proper medical care and medications. Program staff were considerably less likely to report that they helped children

Figure 21: Direct Assistance to Children
(N = 66 Children)



Leslie and Carl B.

Mr. and Mrs. B., age 56 and 33, have been married for over ten years and have two sons, Jeff and Greg, who are 11 and 12 years old, respectively. Mr. B. is not mentally disabled, although he has only one leg and has difficulty using his prosthesis. He does seasonal lawn work for a golf course. Mrs. B. is mildly mentally retarded, as a result of brain damage from a serious illness at age 14, and she is currently experiencing more physical and memory problems.

This family, which survives on \$850/month, was referred to the parenting program by the school psychologist, who noted that the children were frequently very dirty. The family also has a local department of social services preventive case manager.

Both Jeff and Greg have significant problems. Jeff is diagnosed as mildly mentally retarded; he has a communication disorder; and he is in a special class in school. His teacher reports that he often comes to school dirty and that he rarely does his homework. Greg, although not disabled, is two years behind grade level in reading and math. He also shows signs of serious emotional problems, including the inability to form and maintain relationships with other children and adults, assaultiveness towards other children, and a tendency to collect and hide weapons. Greg also frequently comes to school dirty.

Although Mr. and Mrs. B. are characterized as having a good relationship, both boys are verbally abusive to their parents and other adults, and both have been receiving counseling services for several years.

The aide from the parenting program spends at least 15 hours a week with the family, assisting with household chores, parent training, transportation to doctors' appointments, and coordination with the children's school programs.

Although the two boys are having considerable problems, the parenting program staff report that the situation is much better as a result of their weekly intervention. The staff remain concerned about the boys, however, because they have no friends and are very difficult for the parents to manage. Staff added that these issues may become even more serious as the boys become teenagers.

with other more discretionary activities, like providing play and social opportunities (6%), assisting with homework (6%), and offering direct advocacy on behalf of individual children (9%).

Access to Other Community Services

The data also indicated that the vast majority of families were accessing services from at least one other program. In some cases, families were accessing services from other programs run by the sponsoring agency of the parenting program, but equally commonly, these families were accessing programs sponsored by other community agencies.

At least one parent in 24% of the 41 families in the Commission's initial sample attended a sheltered workshop (17%), a supported work program (5%), or a day treatment program (2%). More than one-third of the families (38%) had at least one family member enrolled in a mental health counselling or therapy program. Twenty-two percent (22%) of the families received home health care at least twice monthly, and 51% of the families were enrolled in local WIC (nutritional/food supplement) programs. Finally, more than one-third of the families (37%) had regular contact with local child protective and/or preventive services case workers in their community.

Of note, children were considerably less likely than their parents to be receiving direct services from other programs or agencies. With the exception of WIC services and local child protective and preventive services, the only outside service that more than 10% of the children received was enrollment in a preschool or early intervention program. Despite this observation, however, more than half of the preschool-age children (62%) were *not* enrolled in any preschool, early intervention, or other public school program.

Informal Supports

Formal program services were also augmented with informal extended family and community supports for most families. Program staff reported that 95% of the 41 families in the Commission's initial sample had at least one extended family member living in the community or nearby. Simultaneously, however, it was not uncommon for program staff to report that extended families shared many of the same difficulties as the enrolled families.

Although the study design did not incorporate data collection on this point, reports of significant poverty, alcohol or drug abuse problems, and domestic violence, as well as cognitive limitations among extended families, were frequent. In many cases, program staff explained some of the problems of their enrolled families as extending over several family generations.

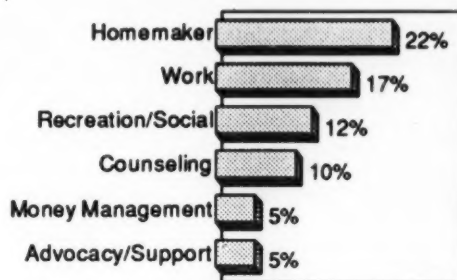
During home visits to the 25 families in the second sample, the Commission attempted to discriminate between the "presence" of extended family and "actual support" from extended family. Paid aides and volunteers reported that about half of these families (56%) received help from their extended family.

Unmet Service Needs

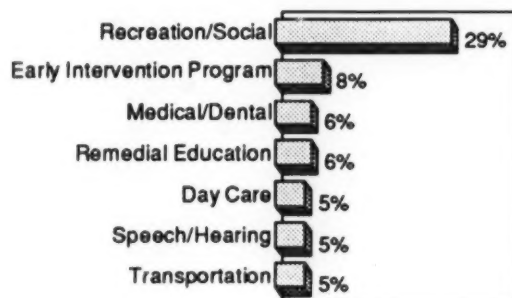
All of the programs indicated that, despite their efforts, most of their families continued to have unmet service needs. For most families served, program staff simply wished that they could be there to help more often, focusing on preventing problems and crises, rather than coping with them after the fact. Program staff also reported that 30 of the 41 families (73%) in the initial sample had at least one specific unmet service need (Figure 22).

- ☐ Almost one-fourth of the families (22%) were reportedly in need of homemaker services.

**Figure 22: Unmet Service Needs of Families
(N = 41 Families)**



**Unmet Service Needs of Children
(N = 66 Children)**



- ❑ Twelve percent (12%) of the families were reportedly very isolated and needed some structured social and recreational activities. In addition, program directors at all programs indicated that most of their families had less severe unmet socialization needs.
- ❑ Ten percent (10%) of the families needed mental health counselling services.
- ❑ Five percent (5%) of the families needed money management services.

Data pertaining to the 66 children living at home with these 41 families identified further gaps in services. In total, program staff reported that 61% of the 66 children had at least one unmet need. As discussed in Chapter III, few of these children enjoyed regular play activities with children outside of their family, and program staff indicated that almost one-third of the children (29%) clearly suffered from limited social and recreational activities.

The second most common unmet service need for the children was access to early childhood intervention, educational, and day care programs, identified as needed for 19% of the children. Smaller percentages of the children were identified as having unmet needs for mental health counselling (3%), medical or dental services (6%), and/or speech or hearing services (5%).

Chapter V

Discussion

Parents who are mentally retarded are not all alike. In many respects, as a group, they are as heterogeneous as parents without cognitive limitations. In part, this heterogeneity derives from the parents' varying cognitive abilities, but it is also influenced by the presence or absence of other specific strengths or problems and disabilities.

Families Differed in Skills, Problems, and Supports

Some of the parents studied were very independent in daily living skills, held competitive jobs, and were able to handle many of the basic parenting tasks with little help. Others, however, lacked many daily living skills and even the most basic parenting skills, including how to feed and bathe a baby or to detect obvious signs of illness. The parents also differed significantly in the degree to which concomitant problems, ranging from severe poverty to domestic violence to problems with alcohol and substance

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abuse, complicated their lives. Additionally, as with all parents, the parents with mental retardation whom we studied differed in their parenting styles, their estimation of the time they should devote to parenting, and their willingness to make personal sacrifices to accommodate their children's needs and wishes.

The parents in our samples also differed significantly from one another in terms of the presence of formal and informal supports in their lives. It appeared that parents with more formal in-home services and/or more informal supports from family members or friends had an easier time.

Access to early intervention school programs for young children and supportive housing arrangements was especially helpful. In-

This study also suggested that most parents with mental retardation require assistance and training in parenting tasks and that most will require this assistance and training long-term.

home assistance several times a week, together with transportation and assistance for medical appointments, shopping, and meeting with school officials were also important services for many of the parents. The presence of caring and helpful family members who stopped by several times weekly and/or who could be counted on in the event of an emergency also made a tremendous difference.

Ongoing Training and Assistance Usually Needed

Notwithstanding these differences, however, this study also suggested that most parents with mental retardation require assistance and training in parenting tasks and that most will require

this assistance and training long term. When the children are very young, this assistance takes on a very concrete form, as parents often need training in learning how to hold the baby, bathe the baby, change diapers and dress the baby, comfort and pick up the baby, make formula, etc. As their children became toddlers, most of the parents in the study needed other types of assistance in learning how to make the house or apartment safe for the toddler, how to toilet train the toddler, how to discipline the child positively and consistently, and how to prepare regular and nutritional meals.

Most of the children in the families studied were very young, but based on the small sample of children five years of age and older, as well as the few older children still in their parents' custody, it appeared that parents with mental retardation may have a more difficult time as their children become older and present challenges to their authority. While older children are more independent and require less hands-on parental help, they also present different parenting demands in dealing with school officials, homework, and making the day-to-day judgments about some freedom for the child versus reasonable supervision.

These changes in the parenting tasks for older children require ongoing parenting training and support. Additionally, parents are likely to become more easily frustrated as their children

Similar to their parents, the children in the families studied differed significantly in how well they were doing.

become older, both because the children may be more oppositional to the parents' wishes and because the parents' cognitive limitations may adversely impact on their personal resources to deal with these contentious situations calmly and confidently, especially in instances where the

children may be more able cognitively than their parents.

Similar to their parents, the children in the families studied differed significantly in how well they were doing. Although for many children their basic needs were met and they were

Perhaps the most outstanding observation of this study was the prevalence of parents with mental retardation in each of the communities of the eight parenting programs.

perceived as meeting most developmental benchmarks, there was a high incidence of children with identified disabilities (53%), and the percentage of children with identified disabilities increased with the children's age. Additionally, most of the families studied had had at least one child removed from their custody, as least temporarily, due to allegations of abuse or neglect. Social isolation and having few friends were also common among the children studied.

Unaddressed Public Policy Issues

Perhaps the most outstanding observation of this study was the prevalence of parents with mental retardation in each of the communities of the eight parenting programs. Within a short time of opening, all of the programs were full, and most had at least one family on a waiting list. It seemed that once the services of the new parenting programs became known in their communities, referrals of parents who were mentally retarded were plentiful.

Many public policy decisions, led by deinstitutionalization and the tenets of normalization and inclusion in service planning for

persons with mental retardation and developmental disabilities, have encouraged adults who are mentally retarded to decide to have children. Unfortunately, while public policy has implicitly encouraged this development, it has not addressed the long-term needs of most of these individuals as they do become parents. Indeed, the Commission's review of the literature indicated that this preliminary study of 54 families headed by a parent who is mentally retarded is one of the largest and most comprehensive studies of these families and their needs that is available.

In all of the communities visited, the Commission also noted that existing local child protective and preventive services agencies were ill-equipped to address the needs of parents who were mentally retarded. On the one hand, few staff in these agencies had special training in serving adults with cognitive limitations. More importantly, however, these programs are crisis oriented and not equipped to provide long-term support services that parents who are mentally retarded will require.

The Commission also noted that existing local child protective and preventive services agencies were ill-equipped to address the needs of parents who were mentally retarded.

A Need for Special Intervention Strategies

Public policy has also not addressed the question of whether *special and enhanced* parenting training and support services should be developed for parents who are mentally retarded. Some observers will note that, aside from their mental retardation, the parents in this study share a common profile with many other parents who are having difficulties and may

have come to the attention of their local child preventive and protective services (Brodeur, 1990; Madsen, 1979). These observers question if separate and/or specially tailored support programs are needed, or even desirable, for parents with mental retardation, as such separation may serve to stigmatize these parents further.

The Commission came to appreciate that discounting the primary impact of cognitive limitations in working with parents who are mentally retarded would be imprudent.

These observations of the commonality between parents with mental retardation and other parents encountering difficulties have superficial validity, but there are more profound differences. Despite the common concurrence of poverty, troubled childhoods, domestic violence, trouble with the law, and alcohol and substance abuse in both groups of families, the Commission came to appreciate that discounting the primary impact of cognitive limitations in working with parents who are mentally retarded would be imprudent. Similarly, although it was true that some of the parents in our study diligently shunned the label of mental retardation, it also appeared that cognizance of the parents' disability was critical in designing effective strategies to help them meet acceptable parenting expectations.

Repeatedly, parenting program staff working with the parents studied reported that they needed to use different, more hands-on teaching strategies and more repetition, reinforcement, and monitoring in working with parents who are mentally retarded, and that the traditional interventions of caseworkers from local child preventive and protective services were often ineffective. In particular, the parenting program staff asserted that child abuse prevention programs more geared toward "telling" the parents

what to do, rather than modelling appropriate interactions and skills alongside the parents in the home, were not usually effective.

Program staff reported that they needed to use different, more hands-on teaching strategies and more repetition, reinforcement, and monitoring in working with parents who are mentally retarded

Most critically, parenting program staff asserted that an underlying difference for these parents was that most would not quickly resolve their difficulties, and would need services for years to come. Although parenting program staff confirmed that, with support services, most parents who were mentally retarded functioned more effectively as parents, they also affirmed that, *in most cases*, the services were *not able* to make enduring changes in the parents' capacities to meet the changing challenges of parenting on their own.

Commission staff also noted that it was easy for professionals not trained in working with people with cognitive limitations to "misread" the abilities and intentions of parents who are mentally retarded. Most of the parents in the sample functioned in the higher levels of retardation, and most had struggled "to pass" as nondisabled in their communities for years. Thus, parents were sometimes reluctant to acknowledge what they could not do or did not understand, and even more frequently, parents could sometimes do a specific task in isolation, but they would become easily confused if they had several tasks presented at one time or if a particular aspect of the task changed.

The Commission heard numerous examples where misreading a parent's abilities led child prevention or protection caseworkers to overestimate the parent's capabilities or to ascribe his/her failure to comply with recommendations as oppositional, rather than simply a reflection of his/her confusion or misunderstanding. Having staff trained and/or experienced in working with adults with mental retardation seemed to be an important protection to assist in overcoming this difficulty.

Conclusions

In summary, several tentative conclusions can be stated based on this study of 54 families headed by one or two parents who are mentally retarded.

- *Like all parents, parents who are mentally retarded represent a heterogeneous group of individuals, with very variable strengths and needs. Despite this variability, however, most require substantial help and assistance with parenting and will continue to need help for years to come.*

It was easy for professionals not trained in working with people with cognitive limitations to "misread" the abilities and intentions of parents who are mentally retarded.

- *Parents who are mentally retarded and who receive more formal support services, and/or who have greater informal*

supports from family and friends are better able to meet basic parenting expectations. Service programs which successfully keep parents who are mentally retarded engaged in and committed to services and which strengthen the informal supports of family and friends can make a substantial positive difference in ensuring the well-being of both the children and the parents.

- Access to early intervention preschool programs for young children and supportive housing is particularly critical for programs serving parents who are mentally retarded. Service access agreements with local providers offering these services are important assets to programs serving parents who are mentally retarded.
- In recognition of the fact that the cognitive limitations of parents who are mentally retarded are life-long and that the tasks of parenting with which the parents will need assistance will change, and in some respects become more and not less challenging as the children become older, programs serving parents who are men-

tally retarded should be funded adequately to offer training and in-home support services to families long term.

- Programs serving parents who are mentally retarded need strong risk management procedures to ensure that children are not neglected or abused and that they receive the proper nurturance, nutrition, and medical care for normal physical, emotional, cognitive development. Neglecting to ensure these risk management procedures will not only place individual children at unnecessary risk of harm, but it will also impair the program's ability to evaluate the benefits of its services objectively.
- Programs serving parents with mental retardation require professional supervisory staff skilled and experienced in working with parents with cognitive limitations who can assure proper training, supervision, and guidance for front-line staff helping the parents. Without this expertise, parenting and child preventive programs are at risk of misunderstanding and/or overlooking critical service needs of the parents and children.

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